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LONG-TERM CARE

HEARING BEFORE THE COMMITTEE ON LABOR AND HUMAN RESOURCES UNITED STATES SENATE ONE HUNDRED FIRST CONGRESS FIRST SESSION

ON
EXAMINING THE ISSUE OF LONG-TERM CARE, FOCUSING ON WAYS TO
BUILD AND IMPROVE ON PAST EFFORTS

MARCH 13, 1989
CHICAGO, IL

Printed for the use of the Committee on Labor and Human Resources



U.S. GOVERNMENT PRINTING OFFICE
WASHINGTON : 1989

20-099

For sale by the Superintendent of Documents, Congressional Sales Office
U.S. Government Printing Office, Washington, DC 20402

5541-49

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LONG-TERM CARE

MONDAY, MARCH 13, 1989

U.S. SENATE,
SUBCOMMITTEE ON AGING OF THE
COMMITTEE ON LABOR AND HUMAN RESOURCES,

Chicago, IL.

The committee met, pursuant to notice, at 10:00 a.m., at Central West Regional Center, 2102 West Ogden Avenue, Chicago, IL, Senator Paul Simon, presiding.

OPENING STATEMENT OF SENATOR SIMON

Senator SIMON. This is a hearing regarding long-term care for the Senate Labor and Human Resources Committee. I had been holding hearings in Illinois, and we have been holding hearings around the Nation on this problem of long-term care. What we want to do is to find some answers and we will hear testimony today. We have 9-10 people slated. We are going to ask each of them to keep their formal remarks to 3 minutes each, and then I will have some questions. We also have several groups that I will acknowledge shortly, who will be submitting statements for the record. Unfortunately, at these hearings we just can't get in everyone who wants to make a statement.

The problem is a pressing problem. And what we want to do is to find answers that make sense. Frankly, we want to avoid the mistake that was made in what is called Catastrophic Care where, frankly, what was done was well intentioned, but it had two basic defects.

Number one, it imposed a tax on those over 65 on the basis of income. Those who pay the highest taxes of any citizens in our country today are those over the age of 65 who are middle income people. That just doesn't make sense. I don't believe in a tax on the basis of age, whether it is over 65 or 18 to 25 or 30 to 40, or any other group.

The second thing that was wrong is it does not cover long-term care. For most of us, fortunately, are not going to have a need for long-term care and those who do, fortunately, most of it will be for a very short term. Only 2 percent of us between the ages of 65 and 74 will need long-term care, but about 22 percent of us over the age of 85 will need long-term care.

The good news is we are living longer; we are eating better; the air we breathe is cleaner; the water we drink is cleaner and the food products we have, we eat, are generally better. When Social Security passed, and there is one or two of you out here who re-

member along with me when Social Security passed, the average American lived to be 58. We now live to be an average of 75. When some of us were young, I can spot a few out here who will remember this along with me, it was very rare to hear about anyone celebrating a 50th wedding anniversary. Today it is fairly common because we are living longer. But for people who have to take advantage of long-term care we have to find answers that are better than the answers that we have right now.

First of all, we ought to be encouraging at home care as much as possible. Congressman Claude Pepper and I have a bill that says if you have the demand for long term care and you can continue to live at home we ought to encourage that. About 30 percent of the people who go to nursing homes don't really need to go to nursing homes. Our bill says you can receive at home assistance up to two-thirds of the cost of nursing home care.

A very typical situation here is an older couple living together, the woman is becoming somewhat frail, the man suffers a stroke, he can't bathe himself. The family lives 1,000 miles away, they don't know quite what to do with dad. And the woman is too frail to take care of just simple things like bathing him and that sort of thing. So the family sends dad to a nursing home. We think there are better answers.

I think Congressman Pepper's bill and my bill really does meet that particular need. We do not have the answer yet for how we provide long-term care and that is why we are holding these hearings. We want to come up with some good legislation to address this problem.

There are only two industrial nations that do not take care of their parents and their grandparents if they need long-term care, that is South Africa and the United States of America. We can do better than that. And that is what this hearing is all about. And let me just add, it is good to see so many people here who are showing an interest in this problem, and I am very, very grateful to you. If we have time after this hearing I am going to try and open this up to anyone else here, and I think there is one microphone in the back of the room for anyone else who wants to add something. I can't guarantee you we are going to do that, but we are going to try and do that if we can keep my questions brief and the panel brief.

And, Phoebe, you have a list of the organizations that I should be acknowledging. There are some groups that asked to testify who will be submitting statements. Let me just add that any of you who want to submit statements for the record so that my colleagues in the Senate and their staffs who take a look at this record can see it, will submit those statements within the next week, we will include that in the record so that you will have a chance to be of assistance to others.

[The prepared statement of Senator Simon with attachments follows:]

PREPARED STATEMENT OF SENATOR SIMON

We convene this hearing today to discuss the issue of long-term health care. For months now, I have been holding town meetings,

forums and discussions across the State about the need for a comprehensive long-term care policy that is based on the social insurance concept.

In the coming months, I hope to take the information, views and concerns I have gathered and introduce a piece of legislation on this. I'm here today to get your input.

The aging of our society has been described as a 20th century miracle. The quality of life for most elderly Americans has improved dramatically over the 1st quarter of a century. Research and preventive efforts have made all of us healthier. One effect of a healthier America has been increasing numbers of Americans have become elderly and we now must meet the challenges of old age.

When Social Security passed, the average American lived to be 58. We now live to be an average of 75. And very shortly we are going to see an explosion in this demand for long-term care. And we are either going to devastate seniors and families or we are going to meet this problem in a constructive way.

People aged 85 and older are more than four times as likely as those aged 65 to 74 to need long-term care services. There is a great need for a comprehensive bill to address the health care needs of our elderly and disabled citizens.

Last year, I joined Senator George Mitchell in the introduction of a long-term care proposal for the chronically ill. As I indicated then, the proposal did not go as far as I think we should on long-term nursing home care. It troubled me that that plan would provide Medicare benefits for nursing home stays once a person had spent 2 years there; once low- and middle-income elderly had lost everything for which they worked. I am here today to build and to improve on past efforts.

I also joined Senator Ted Kennedy in introducing "LifeCare". For America, Lifecare in the 1990's would be what Social Security was in the 1930's and Medicare was in the 1960's. Lifecare would be able to help the American family afford long-term care for parents, grandparents, relatives, friends and other loved ones without having to sacrifice the dreams of a home, college education for their children or basic necessities. Long-term care is a family issue, a women's issue, an elderly issue and a disability issue. It is about families who are being devastated by the need for long-term care.

Sixty-three percent of patients in nursing homes are there for less than 6 months. Lifecare would provide a minimum of 6 months coverage. It also would establish a voluntary insurance plan for those over 45, who seek to insure themselves against unlimited, longer stays

This bill would provide a blueprint for how our Government should take care of our Nation's elderly, sick, physically and mentally ill, and provide for long-term care. Lifecare would provide relief for the American family of today and of the future.

Finally, this week Senator Rockefeller, Senator Mitchell and I will be introducing legislation that would support State use of Medicaid to offer a defined package of home and community-based long-term care services to the elderly and disabled. Benefits available could include adult day care, nursing care, homemaker/home health aide care, chore services, respite care, physical, occupational

or respiratory therapy, speech-language pathology, medical supplies, home-delivered meals, day treatment, and hospice care. Eligibility is set at two activities of daily living or Alzheimers patients. It is a small step in the right direction.

I receive letters from senior citizens asking for help when their spouse is in a nursing home and they have spent their life savings in less than a year and are now forced to go on welfare and receive Medicaid. Eighteen months ago, a gentleman from Greenville, IL, starved himself and lived without air conditioning so that his wife could stay in a local nursing home.

Recently, a woman from Riverside, IL, wrote this:

A friend of mine, Mary Ingorvato, was recently admitted to a hospital for a broken foot and a cracked chest bone as a result of a fall. After 3 days, discharge plans were in the making. She was bedridden, and suffered from diarrhea and fever. There was no possible way in which she could care for herself, for she was still ill. The doctor said that she needed further medical care, but was informed that Medicare would no longer cover her hospitalization. Thus, she would have to be released. This seems strange, being that she is allowed 60 days plus on Medicare. Once she was kicked out of the hospital, there would be no one to care for her and she has no money for a nursing home.

After one week at home, she returned to the hospital via ambulance. The diagnosis was two cracked vertebrae. Her spine was deteriorating and after immediate medical treatment at the hospital it became evident that a nursing facility was the only answer. Medicare does not pay for this and neither does supplemental hospital care. She has no money. Her life savings is now enough for 2 months in even the lowest cost home. Prior to her health problems, she managed beautifully on \$460 per month. Additionally, no nursing homes want her. Certain facilities will not accept public aid patients. In many cases patients must make a \$40,000 deposit. Caring for senior citizens has become a flourishing business, and it provides a service only the wealthy can afford.

It is a shame that the hard-working, upstanding citizens in our country are reduced to poverty because America lacks a long-term care plan to serve the very basic need for adequate health care and related medical services.

I ask for support on this very important issue today and hope that we can address this great need before the 101st Congress adjourns. I look forward to the testimony presented today and I hope that together we will be able to forge a policy that is fair and humane to both old and young alike.

We must ensure that all Americans share in the dignity of our Nation and that a dignified nation—a dignified America—cares for our aging, disabled and mentally ill citizens. This is not a burden. It is the just and right thing to do.

news from

PAUL SIMON

U.S. SENATOR

(FOR REFERENCE ONLY --
EARLIER VERSION OF BILL)FOR IMMEDIATE RELEASE
Thursday, April 21, 1988CONTACT: David Carle (202) 224-7115
Patricia Huey (202) 224-7111
ILLINOIS**SIMON BACKS MAJOR LONG-TERM HEALTH CARE BILL**

WASHINGTON -- U.S. Sen. Paul Simon, D-Ill., is one of six senators heading an effort to enact new legislation to expand Medicare health insurance to cover the long-term health care needs of older Americans.

In a news conference here on April 21, Simon joined Sen. George Mitchell, D-Maine, chief sponsor of the plan, and other senators in announcing the effort.

The bill would expand Medicare health insurance to cover long-term care services, including nursing home stays, home health care and respite for family caregivers.

Simon said the bill will relieve many older Americans and their families from the crushing debt often associated with long-term health care.

"It's not right that after a lifetime of hard work, of supporting yourself and raising a family, that the onset of health problems should cost you your independence," he said. "But that is precisely what happens to many of our parents and grandparents. It is time to offer that independence and to protect our families."

The program is self-financing, using three revenue sources dedicated to a new long-term care trust fund. Cost estimates will be firmed up in congressional hearings on the measure, but early estimates place the cost of the program at about \$13 billion per year.

The legislation builds upon a plan introduced last year by Simon and Rep. Claude Pepper, D-Fla., that would expand Medicare insurance to cover long-term home care.

Mitchell credits Simon's earlier efforts in helping to clear the way for the new initiative. "In the past year, no person has done more to elevate this issue (long-term health care) to the forefront of national concern and consciousness than Sen. Simon," he said.

The bill has these features:

RESPITE CARE. A respite care benefit would be available for charges of up to \$2000 annually with a 50 percent copayment (i.e., a \$1000 benefit per year). The benefit would provide in-home or day care assistance to relieve the primary caregiver.

HOME HEALTH BENEFITS. Those eligible could receive benefits to help with chronic home care services, along with homemaker and chore aide services.

NURSING HOME SERVICES. Under the plan, Medicare would begin to reimburse for these costs after two years -- a period Simon hopes to shorten or eliminate as the bill moves through Congress.

FINANCING. The basic Part B Medicare premium would be increased \$2 per month. The limit on the amount of earnings (\$45,000) subject to the Medicare Hospital Insurance Tax (1.45 today) would be repealed -- a change that would affect only those 5 percent of workers who earn more than \$45,000 in individual income (not family income). A 5 percent surtax would be levied on the transfer of assets by gift or

inheritance in excess of \$200,000, to be computed after the unified credit is taken. Under current law, the unified credit has the effect of exempting from the tax estates with net assets of less than \$600,000.

PAUL SIMON
ALBANYCOMMITTEE
LABOR AND HUMAN RESOURCES
JUDICIARY
FOREIGN RELATIONS
BUDGET

United States Senate

BACKGROUND	BACKGROUND	BACKGROUND
BACKGROUND	LONG-TERM	BACKGROUND
BACKGROUND	HOME HEALTH CARE	BACKGROUND
BACKGROUND		BACKGROUND
BACKGROUND	BACKGROUND	BACKGROUND

Office of U.S. Senator Paul Simon

Illinois

NURSING HOMES NOT ALWAYS THE ANSWER. A common misconception is that large numbers of older Americans live in nursing homes. In fact, 1.3 million Americans -- fewer than 5 percent of those over age 65 -- live there. Among the 95 percent who do not, one in five needs help performing at least one daily activity -- dressing, bathing, walking, shopping. After age 85, at least one in three Americans needs help with the basic tasks of daily living.

COSTLY CARE. Older Americans and their families spent \$3.5 billion in 1984 for visiting aides, therapists and housekeepers -- more than twice the \$1.7 billion spent in personal outlays for hospital care.

More than 85 percent of Americans are uninsured or under-insured for long-term care.

MEDICARE DOES NOT COVER. Although most Americans do not realize it, Medicare will not pay for long-term care. Before Medicaid can help, individuals or couples must exhaust their own resources, becoming poor enough to qualify by "spending down" their income, savings and other assets. Long-term care usually saps the life savings of even the thriftiest middle- and lower-income families with brutal speed and forces countless seniors to close out their lives as paupers.

HARVARD LAW SCHOOL researchers, studying the issue of long-term care in nursing homes, found in 1985 that nursing home costs would bankrupt 46 percent of a sample of single 75-year-olds in Massachusetts in just 13 weeks. By the end of a year in a nursing home, 72 percent would have nothing left.

OF MARRIED ALZHEIMER'S patents getting care at home, 47 percent are impoverished within the first year. And millions of seniors with crippling arthritis or other chronic conditions requiring long-term care at home get no protection. Simply stated, the costs of long term care at home are beyond the reach of the typical working or retired household.

IN A TYPICAL CASE, a Jackson, Miss., couple went through \$49,000 in savings during the husband's seven years of illness, including seven strokes and a heart attack. He died five weeks after entering a nursing home and his wife was left penniless. She had to sell his gardening tools and a small tractor to pay for his \$1,600 funeral. Caring for chronically ill or disabled working-age adults or children presents similarly impossible burdens on countless families.

'CATASTROPHIC CARE' coverage under discussion in the Congress does not address the problem of long-term care.

THE POVERTY RATE among older Americans generally is highest among women, minorities, those who live alone, the unmarried and rural residents. Thirteen percent (3.5 million) of the 30 million Americans over age 65 are below the poverty line. Another 8 million are economically vulnerable. The average income of a woman over 65 is \$6,313.

NEGLECTING MEDICAL NEEDS, even minor ones, eventually leads to hospitalization that is costly to individuals, their families or to the government.

THE PEPPER-SIMON PLAN supports the heroic efforts of America's families to help frail parents and other chronically ill family members live with dignity and adequate care at home.

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F A C T S H E E T

Long-Term Home Care Family Protection Act**SPONSORS**

House: Rep. Claude Pepper

Senate: Sen. Paul Simon

FAMILIES CRUSHED BY HOME CARE DEBT

Eighty percent of catastrophic health care expenses are for long-term care provided outside of hospitals. To meet these costs, families often are forced into bankruptcy or poverty. The Long-Term Home Care Family Protection Act tackles this huge unmet need by offering a new, self-financing, "Long-Term Home Care" benefit under Part A of the Medicare program to aid chronically ill seniors and disabled adults and children, while also relieving severe financial burdens on their families.

BENEFITS AND ELIGIBILITY

The Long-Term Home Care Family Protection Act defends families against the catastrophic costs of chronic illness for seniors, working-age Americans and children needing home care. The plan recognizes that long-term catastrophic home care costs are not simply a problem for the elderly but also for millions of young families crushed by debt in caring for parents or other family members. Home care assistance would be available under the act only when prescribed as essential by a physician and would be closely monitored and managed to assure efficiency and cost effectiveness. Such care could include:

Nursing Care
Homemaker/home health aide services
Personal therapy/rehabilitation
Physical therapy/rehabilitation
Speech therapy/rehabilitation
Respiratory therapy/rehabilitation
Medical social services
Personal care services
Patient and family education and training
Medical supplies
Durable medical equipment

Help would also be available to chronically ill seniors, disabled persons and children who have been certified by a doctor to require significant assistance with normal activities (eating, bathing, dressing, home mobility and toileting). Children dependent upon medical equipment would also be eligible for long-term home care.

(continued - see other side)

BENEFITS AND ELIGIBILITY *continued*

Many of those eligible would need costly nursing home or hospital care in the absence of proper home health care. Examples of individuals who should benefit:

- Frail elderly persons with advanced Alzheimer's Disease or Parkinson's Disease
- Children born with chronic lung ailments
- Stroke victims
- Working-age Americans left paralyzed by accident, injury or disease
- Children and older Americans with long-term, debilitating cancer

QUALITY CONTROL

The strong quality assurance components of the Long-Term Home Care Family Protection Act include mandatory training and regular review of care givers, a home care consumer bill of rights, community review boards and effective enforcement mechanisms to ensure compliance with quality of care standards.

COST CONTROL

Costs would be tightly controlled by holding monthly payments to 75 percent of the monthly Medicaid rate for skilled nursing home services. Payments for children needing medical technology could not exceed the cost of providing similar services in a hospital or nursing home. Numerous national and state studies have shown the value of providing case-managed home care services that cost a fraction of the cost of institutional care.

FINANCING

The Long-Term Home Care Family Protection Act is fully and progressively self-financed. The new home care benefit would be completely financed by eliminating the cap (\$45,000 in 1988) on income subject to the Medicare payroll tax of 1.45 percent. This change would affect only those 5 percent of workers who earn more than \$45,000 in individual income (*not* family income). The change would generate approximately \$6 billion each year over five years. The bill specifically prohibits use of any general revenue funds or other Medicare trust fund monies to pay for long-term home care.

FOR RELEASE: 5:00 PM, March 17, 1988

PAUL SIMON

Contact: David Carle 202/224-7115
Chris Ryan 202/224-7023

U.S. SENATOR

ILLINOIS

BACKGROUNDER

ON THE NEED FOR

LONG-TERM HOME CARE FOR ALL AMERICANS

- * APPROXIMATELY 1 MILLION AMERICANS EACH YEAR BECOME IMPOVERISHED DUE TO THE COSTS ASSOCIATED WITH LONG-TERM ILLNESS. Within this group, more than two thirds are elderly. Yet, a high percentage families with ill children.
- * 80 PERCENT OF CATASTROPHIC HEALTH CARE EXPENSES ARE FOR LONG-TERM CARE provided outside hospitals. With the exception of Medicaid, the health program for the poor, existing government health programs cover only a minute percentage of the costs of long-term care. Medicare pays for only one percent of nursing home costs.
- * Medicaid provides substantial assistance for nursing homes and other long-term care expenses. However, the rules of eligibility are so stringent that these benefits are available to less than half of those with incomes below \$11,000 annually.
- * For illnesses that may require long-term care, ALL AMERICANS ARE AT RISK, since insurance for the following is simply NOT available:
 - the 20 million Americans who suffer chronic heart conditions;
 - the 10 million Americans with chronic lung disease;
 - the 10 million children with chronic health conditions;

- the 5 million Americans who have cancer;
- the 3 million Americans with Alzheimer's disease;
- the more than 2 million Americans who suffer chronic mental illness;
- the 500,000 Americans who have Parkinson's disease;
- the over 4 million accident victims who require hospitalization and therapy each year, nearly 500,000 Americans of whom are left permanently disabled;
- the 700,000 Americans with cerebral palsy, the 100,000 with Huntington's disease, and the more than 50,000 with Lou Gehrig's disease (amyotrophic lateral sclerosis).

* Simon is the sponsor of S. 1616, the Long-Term Home Care Family Protection Act, to provide comprehensive home care to technology-dependent children, along with persons who need assistance with two or more activities of daily living (ADL's). Simon's bill is completely self-financing and progressively financed. The cap on income subjected to the Medicare payroll tax -- 1.45 percent on approximately \$6 billion annually over a five year period. As 95 percent of the working public make below \$45,000 annually, only 5 percent of working Americans would be affected. Some 100 diverse national organizations have endorsed the Simon measure.

* Currently, once a person becomes terminally ill, it is unlikely that the person will become self-sufficient. Most private insurance coverage and Medicare benefits come to an end. Meanwhile, under this scenario, we have seen life savings depleted and victims fall into poverty in order to qualify for Medicaid. The average allowable assets under Medicaid are \$3,000 for a couple and \$2,500 for an individual. The current cost of nursing home care ranges from \$15,000 to \$70,000 and averages around \$25,000 a year.

* Federal officials have been discussing long-term health care since 1946, when a Senate subcommittee first proposed a comprehensive system of health care for Americans of all ages. Forty-one years after a program of this nature was considered, this nation still lacks a meaningful system of long-term care. The United States remains as one of the two remaining industrialized nations (South Africa is the other) not to have filled the long-term care gap.

Senator SIMON. Those organizations submitting written testimony are Blue Cross and Blue Shield, the Council for Jewish Elderly, and I understand Constance Steinau is here from that group. Are you here, Ms. Steinau? Right back there. Thank you for being here. The Illinois Association of Homes for the Aging. Any of these groups who are here please stand. The Illinois Department on Aging, Ron Weiss, very happy to have you here. Thank you. The Older Women's League, all right, thank you very, very much. The Paralyzed Veterans of America, I have seen them, Tom Duncan and George Dempsey are here representing them. The Chicago Geriatric Society, Dr. Joanne Schwartzberg, thank you very much. She has been taking an interest in long-term care for some time. Elaine Hursh, Department of Citizens Rights for the Attorney General's Office, happy to have you here. Other organizations and individuals submitting statements include: The Chicago Advisory Council on Aging and Chicago Advisory Council on Disability, Illinois Department on Aging, C. Jean Blaser, Ph.D., June Poniatowski, Chicago Gray Panthers, Ages J. Ranseen, and the Alzheimer's Association.

[The prepared statements of the above organizations follow:]

PREPARED STATEMENT OF THE BLUE CROSS AND BLUE SHIELD ASSOCIATION

Mr. Chairman, and Members of the Committee, the Blue Cross and Blue Shield Association is pleased to submit for the record its comments and recommendations on the issue of financing of long term care. The Association is the coordinating organization for the 75 Blue Cross and Blue Shield Plans across the country. Collectively, the Plans provide health benefits protection for more than 80 million Americans.

We appreciate the opportunity to comment on the appropriate roles for both the private sector and the government in addressing the needs of those who require long term care services. We strongly support the concept of a public and private sector partnership as the best and only viable approach to a national long term care policy. Before commenting on these major issues, we would like to review briefly the current long term care financing problem and describe some of the products offered by Blue Cross and Blue Shield Plans.

Background

Very briefly, the following statistics demonstrate the current long term care financing problem:

- o Approximately 30 million Americans are over age 65. They comprise over 13 percent of our population, but will grow steadily to over 18 percent, or 55 million, by the year 2030.

- o The number of individuals over age 85 -- an age group particularly at risk for needing long term care services -- will grow three to four times as quickly as the general population.
- o Individuals and their families pay over half of total nursing home expenses out of their pockets -- over \$19 billion in 1986. Medicaid pays for most of the rest, but only after a family has exhausted nearly all financial resources.

Blue Cross and Blue Shield Long Term Care Activities

Over the past few years, many Blue Cross and Blue Shield Plans have responded to this emerging problem by developing long term care insurance products. Thirteen of our Plans are currently marketing these products and several more will soon begin offering them.

In addition to care provided in nursing homes, our long term care products typically cover a wide variety of home and community-based health services, including home health visits, adult day care, homemaker services, medical transportation and respite care. These policies may be purchased by persons between the ages of 40 and 84. Premiums vary with age at initial purchase and with the benefit options selected.

Premium rates are set at a level that will, over an expected lifetime, accumulate the funds necessary to meet the increasing need for services in later years.

Due to the lack of data on utilization and costs of long term care, most of the industry's earliest long term care policies were quite restrictive. These policies typically offered nursing home coverage and required prior hospitalization before individuals could receive these benefits. Alternative levels of care, such as home care or custodial care were seldom offered.

In contrast, long term care insurance policies recently developed by Blue Cross and Blue Shield Plans tend to offer benefits that meet a variety of long term care needs. For example, several Blue Cross and Blue Shield Plans offer more traditional "service" benefits which base payment on the cost of services received rather than a fixed 'indemnity' benefit which establishes a set dollar per day benefit. This type of payment structure assures individuals that their insurance coverage will keep pace with health care cost inflation. Few policies have prior hospitalization requirements and those that do usually offer this as an option.

Many policies also include individual case management benefits in order to help assess a person's specific needs and provide

them with care in the most appropriate setting. This may include benefits outside of the initial benefit design of the product such as respite and custodial care. Some policies also are designed to protect against inflation by incorporating features such as annual benefit increases (i.e., annual percentage increases in fixed payment amounts for covered services), periodic opportunities to increase benefit levels or paid-up options. All of our products are guaranteed renewable.

A brief description of some of our products illustrates how these features may be combined into a long term care insurance package.

Blue Cross of Washington and Alaska's "Lasting Care" program offers persons aged 50 to 84 protection from the high cost of skilled and intermediate nursing home care, custodial care, adult day care and home health care. Subscribers have the option of 100 percent (up to \$75/day) or 80 percent (up to \$60/day) coverage of the average community cost of nursing home services. Home care is covered for 100 percent (up to \$1,143/month) or 80 percent (up to \$913/month) of eligible charges. An additional \$1,500 in benefits for meals, outpatient prescriptions drugs, medical supplies and durable medical equipment is provided to eligible individuals in the first benefit year, and \$500 for each subsequent benefit year. The policy also provides coverage of hospice care. The policy

is guaranteed renewable, has no prior hospitalization requirement to qualify for benefits and waives the premium after receiving 90 days of benefits.

Blue Cross and Blue Shield of the Rochester (NY) Area offers its product, Care Directions, through a subsidiary which provides coverage in a full range of settings, including nursing homes, adult day care centers and individual homes. Persons aged 21 to 85 may purchase any of six product options. The policy offers the option of 75 percent of the cost coverage or a "service day" approach. The number of service days available varies with the length of coverage chosen, and individuals use up these service days according to the setting in which care is received. For example, one day in a nursing home equals one service day, while one adult day care visit or one home care visit (up to 8 hours) equals only one-half of a service day. Thus, a person who purchases a 5 year policy but needs daily home care services could receive up to 10 years of covered home care services. The policy pays 75 percent of the cost of covered services and includes an inflation protection feature. The policy also offers a "paid-up" option. Under the paid-up option, premiums are payable for a period of 20 years, after which no premiums would be required and benefits for covered services would be payable for the remainder of the insured's lifetime. Medical underwriting is waived for active workers in groups over 100. Group members may also enroll

extended family members at the group rate.

Blue Cross and Blue Shield of Connecticut's "Century Gold Plus" provides coverage for 100 percent of the average community cost of nursing home services (set at \$95/day in 1988) and home health services (set at \$40/visit in 1988) and 75 percent of the cost of homemaker and adult day health care services for persons aged 40 through 79. The policy includes a comprehensive program of case management services and offers a 20 year paid-up benefit option. The policy also offers an optional inflation protection feature.

The Challenge of Long Term Care Financing Products

In spite of the encouraging nature of these new long term care insurance products, a number of problems remain which inhibit more rapid development of the market.

Public Misperception. First, although more and more attention is being paid to the problem of financing long term care, much of the public continue to believe that they already have coverage for long term care expenses. While this perception is slowly changing, it is important to educate the public about the lack of coverage for long term care.

Lack of Data. Another barrier to widespread coverage is the lack of widely available actuarial experience on which to base

premiums. Although there is a growing body of data on current utilization of nursing home and home health services, it is difficult to use this data to predict utilization under a long term care insurance product. This problem is compounded when projecting costs and utilization 10, 20 or 30 years into the future.

Regulation. Another challenge faced by insurers is the potential for state and federal legislative or regulatory actions. While there has been little regulatory activity in this area to date, insurers are concerned that as the market expands regulators may impose restrictive requirements regarding underwriting, continuation of coverage or minimum standards which would inhibit insurers' flexibility in designing LTC financing products. Additionally, insurers worry that regulators may fail to grant necessary premium increases. Legislators or regulators could develop the mistaken impression that the large reserves for long term care should be used to offset requested premium increases if they do not understand that these funds will be needed to pay for long term care benefits in the future.

Recommendations

In order to assure that long term care services are available on as broad a basis as possible, we believe that there is a need for flexible, innovative private sector options for those

who are able to pay for them and improved public programs to protect those who cannot participate in private programs -- that is, individuals already 85 years old and over, individuals currently suffering from chronic illness, and the low-income.

The Role of the Private Sector. The private sector cannot address the needs of all segments of the population. However, we are confident that, given the proper environment, and our growing experience, the private sector can significantly increase the number of people protected against the cost of long term care.

The Blue Cross and Blue Shield Association, with our member Plans, performed extensive market research and actuarial analyses and used this as the base for designing our long term care products for the private market. Using this research, we have developed a number of recommendations for government action that we believe would make private insurance more widely available.

1) Market Incentives. First, we recommend the establishment of incentives for the sale and purchase of long term care insurance. The most important of these incentives is to clarify that long term care insurance products are to be taxed on the same basis as non-cancellable accident and life insurance. This would permit insurers to set aside a portion

of annual premiums collected, and accumulate interest on these funds on a non-taxable basis.

Insurers would be allowed to do this until the funds are sufficient actuarially to pay for future liabilities for long term care benefits.

We recommend that insurers be allowed to establish such reserves on a tax-favored basis after the insurance has been in force for one year, instead of the current two-year requirement. Under current law, insurers can not establish tax-favored reserves for most types of health insurance until the insurance policy has been in force for two years. Allowing tax free reserve build up after one year would help insurers keep premiums as low as possible.

We also recommend that long term care insurance be given the same tax-favored status granted to group health benefits. Specifically, benefits paid out, and employer contributions for long term care insurance would be excluded from an employee's income. Also, we believe that employers should be allowed to deduct contributions to a long term care plan as a current expense and to offer long term care coverage as part of a cafeteria plan.

Finally, we suggest that individuals be permitted to deduct

qualified long term care expenses and premiums using the limited medical expense deduction allowed under Section 213 of the Internal Revenue Code. This section permits individuals to deduct medical expenses in excess of 7.5 percent of their adjusted gross income.

2) Continued Regulatory Flexibility. Our second recommendation is for continued regulatory flexibility at all levels of government to support the development of a variety of private sector long term care financing mechanisms. The Blue Cross and Blue Shield Association and its member Plans actively participate in and support the development of the long term care Model Act and Regulations by the National Association of Insurance Commissioners as a means of consumer protection.

3) Public Education. Third, we strongly support a government role in clarifying for individuals the nature, extent and risks of potential long term care expenses. Many older people are under the impression that Medicare provides coverage for long term care. We need to increase public understanding that Medicare is designed primarily to cover acute care, and that it does not provide adequate coverage for chronic care or non-acute nursing home care. Public misunderstanding on this issue is clearly a major obstacle to the expansion of needed long term care coverage. The recently approved Medicare catastrophic legislation includes a provision that requires

that beneficiaries be notified as to what Medicare will and will not cover. We believe this will be helpful to beneficiaries.

4) Data Collection. Finally, we believe that the federal government should continue to encourage the collection and availability of cost and utilization data on long term care services.

We are pleased that Blue Cross and Blue Shield organization representatives were included in an Health and Human Services Task Force which met to study how we should gather and organize data on long term care. This data is critical in order to develop effective and sustainable programs with realistic premiums.

We are confident that, with the needed government support, the private sector can increase significantly the number of people protected against the cost of long term care needs.

The Role of Government. The most difficult question Congress must address is the appropriate role for the federal government in the direct financing of long term care benefits. That is, in a public-private partnership for providing long term care protection, who can we expect the private sector to provide protection for and who is appropriately the responsibility of the government?

At the heart of the debate will be the question of whether a new entitlement program should be created to provide long term care or whether the government should assume the responsibility for individuals based on their financial need. This debate will raise many of the same issues as the debate surrounding the Medicare program in the early 1960's. Based on our experience to date in this market and our extensive experience in the health insurance market, we offer some guiding principles for the Congress to consider in this debate.

First, we believe that there should be the greatest possible dependence on private coverage for those who can afford the premiums in order to make federal dollars available for those whose needs the private sector cannot meet. This principle of using private dollars to make federal dollars go as far as possible would apply to either an entitlement program -- for example, an income related waiting period -- or for an entirely means tested program.

Second, long term predictability of government benefits is necessary in order for consumers to plan for their retirement and to feel comfortable purchasing a private policy which they may not use for many years. Long term predictability is essential also for private insurers to design policies that provide good protection.

We are concerned that, unlike the situation with respect to our Medicare supplemental policies, the government cannot count on the private sector using the same "gap filling" model in response to changes in government long term care coverage. Because the nature of long term care policies dictates that premiums be set as much as twenty years in advance of expected benefit use, our ability to adapt our policies if the government reduces or otherwise changes long term care benefits is limited greatly.

We realize that the lack of information related to morbidity, mortality, utilization, and institutional capacity, creates inevitable uncertainty as to what benefits the government can or should sustain over time. In addition to these uncertainties, the government faces fiscal pressures separate and apart from the cost of this program which may well create pressures to modify waiting periods or possibly other benefit changes. For example, this could lead to a situation where someone could purchase a two year private policy only to find, when they need benefits, that there is a three year waiting period for government benefits.

Third, we believe that the concept of budget neutrality is a sound one. In today's fiscal environment, major new programs need to be matched with the revenues to sustain such commitments. Multi-source revenue bases and earmarked taxes are essential.

However, we are concerned that -- in designing a new long term care program as an integral part of the Medicare program -- the Congress give careful consideration to the extent of any additional premium financing from elderly people that may be required. Regardless of whether any new premium would be mandatory or voluntary, there are considerations for either approach. Mandatory Part B premium increases are problematic given the projected expense of Medicare's basic benefits and recently added catastrophic coverage. On the other hand, a voluntary premium would increase the risk that only those who anticipated using the benefits would participate in the program. If so, the premiums for those participating would be extremely high -- to the point of being unaffordable unless heavily subsidized.

Conclusion

In conclusion, we endorse the basic concept of a public-private partnership as the most promising approach to assuring the availability of long term care services. We believe that more discussion and analysis is necessary to determine whether those who need long term care are best served by an entitlement program that uses a waiting period/deductible approach or an approach that focuses federal dollars on those who do not have access to private programs. We would urge the Congress to move ahead as soon as possible to clarify the tax status of long term care products.

We want to thank the Committee for this opportunity and we would be pleased to work with you as you continue to search for ways to finance long term care services



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COUNCIL FOR JEWISH ELDERLY

JEWISH FEDERATION OF METROPOLITAN CHICAGO
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My name is Constance J. Steinau. I am a member of the Governing Board of the Illinois Association of Adult Day Care Providers and the Director of the Health Services Department at the Council for Jewish Elderly. The Council for Jewish Elderly is a comprehensive and coordinated community-based system that provides a wide range of services to help keep older people independent and functioning within their own community for as long as possible. Services provided include transportation, neighborhood drop-in centers, counseling and health services, housekeeping, homemaker, home-delivered meals, in-home companion, group living, respite care, home health, shared housing, intergenerational programs, subsidized apartment buildings and a 240-bed geriatric health care facility. Also included in this continuum of care is an Adult Day Care Center. I am pleased, today, to have the opportunity to address the issues impacting on Adult Day Care and the role it must have as an option in long-term care planning.

The National Institute on Adult Day Care defines Adult Day Care as a "community-based group program designed to meet the needs of functionally impaired adults through an individual plan of care. It is a structured comprehensive program that provides a variety of health, social and related support service in a protective setting during any part of a day but less than 24-hour care. Individuals who participate in Adult Day Care attend on a planned basis during specified hours. Adult Day Care assists its participants to remain in the community, enabling families and other caregivers to continue caring for an impaired member at home".

The population in need of Adult Day Care is made up of individuals having physical, emotional or cognitive deficits which prevent them from socializing in less structured informal programs. Without the availability of an Adult Day Care Center, many would remain isolated in their homes, either alone or dependent on a caregiver for much of their care. Such programs serve not only to prevent premature institutionalization of its clients, but provides much needed respite to those caregivers providing care at home.

While Adult Day Care Centers do exist nationally, and there are approximately 80 centers in Illinois, Adult Day Care has been one of the best kept secrets in long-term care. Lack of public awareness and understanding of what Adult Day Care is, has been a major factor in its under-utilization. While many people have never heard of Adult Day Care, many others think that it's either an extension of nursing home service or a senior center.

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Adult Day Care, although referred to as a single service, is in fact, a constellation of services. The Adult Day Care Center provides managed care for the individual through the development of an individualized care plan. Adult Day Care offers the following basic and optional services:

- ° Opportunity for socialization.
- ° Activities, consisting of planned recreational and social activities suited to the needs of the client, and designed to encourage physical exercise and reality orientation, to postpone deterioration, and to stimulate social interaction.
- ° Nutrition services, including one mid-day meal and snacks.
- ° Transportation access to and from the Adult Day Care Center.
- ° Nursing service, including on-going assessment of nursing care needs, development of health care plan, medication dispensing per M. D. order, health education and counseling.
- ° Social Services, including counseling and planning.
- ° Rehabilitation services, including physical, occupational and speech therapy.
- ° Personal care services, including assistance, where needed, with activities of daily living such as grooming, walking, toileting.
- ° Caregivers are also eligible for counseling, planning and advocacy through Caregiver Support Meetings offered at the Center.

Adult Day Care has been called the fastest growing component of long-term care. More and more people are recognizing the value of having a community location where these vulnerable older people can enjoy supervised therapeutic activity away from home.

A very real barrier to access to Adult Day Care is that of cost. Many of the elderly have depleted savings by paying for essential medical services. Family resources may not be available, especially as the numbers of "old old" are increasing, whose children may be retired and on fixed incomes themselves.

The Adult Day Care providers, often not-for-profit organizations, are also experiencing financial difficulties. The average daily fee for service does not cover the actual cost of providing this multi-dimensional service to its consumers. While centers have been resourceful in finding ways to reduce cost without compromising quality, it is becoming increasingly more difficult.

In the last several years, Adult Day Care Centers are receiving more referrals of individuals with Alzheimer's Disease. The programming and staffing adjustments to accommodate the special needs of these individuals have placed additional financial stress on the centers. To provide quality programming requires more than just a dedicated staff and a strong desire to help. It requires adequate funding.

In Illinois, the State Association of Adult Day Care Providers and the Illinois Department on Aging have taken leadership roles in promoting public awareness, setting quality standards and determining equitable reimbursement levels. These efforts, however, have just laid the groundwork for what will be needed in the future.

I urge this Committee to carry out its responsibility in planning for the long-term care for our aging society and to remember that such care does not only include residential services but a broad spectrum of programs, including Adult Day Care.

Adult Day Care is one bright color in the midst of this spectrum, and must be included in any and all funding discussions of long-term care.

Thank you.

CJS:jf
3/89

OLDER WOMEN'S LEAGUE

NATIONAL OFFICE

TESTIMONY OF THE OLDER WOMEN'S LEAGUE

ON LONG TERM CARE

For a hearing held in Chicago, Illinois by Sen. Paul Simon
on March 13, 1989

The Older Women's League (OWL) would like to thank Sen. Simon for his leadership on the issue of providing long term care services to the chronically ill. We appreciate the opportunity to submit testimony on securing essential long term care services for our nation's chronically ill.

OWL, as you know, is the first national membership organization focusing exclusively on mid-life and older women. We are a national grassroots organization with over 110 chapters in 36 states.

As both a women's and an aging organization, OWL is particularly concerned about persons with chronic health problems, their access to affordable, quality care in the most appropriate setting, and support for the caregiver, both unpaid and paid.

Long Term Care As a Women's Issue

Almost all midlife and older women have a major stake in long term care. The statistics speak for themselves.

- o The majority of persons over age 65 who reside in nursing homes or who need person care at home are women.
- o Three out of every four unpaid caregivers are women, as well as over nine out of every ten paid caregivers.
- o Most elderly in need of chronic care live at home and receive only unpaid care; only five percent receive all home care from paid caregivers.

The Current Problem

For far too long, elderly and disabled persons with chronic conditions have suffered from Medicare's bias towards the treatment of acute medical conditions. This overemphasis on a medical model for Medicare has resulted in the downgrading of daily care, whether convalescent or long term, to so-called custodial status.

The medical model also has contributed to Medicare's almost complete neglect of health promotion, disease prevention, and rehabilitative services designed to regain lost functions or retain current abilities.

The passage of the Catastrophic Coverage Act has only exacerbated the emphasis of our health care system on acute care delivery. While the Catastrophic law contains many important new benefits, such as the prevention of spousal impoverishment and limited coverage of mammograms and respite care, it does not address the truly "catastrophic" costs associated with chronic illness.

Comprehensive long term care coverage--including home care and nursing home care--will move our national health care system toward a more holistic delivery approach, with more emphasis on the care each individual needs and less importance given to where the services are rendered or who performs them.

The Congress must be made aware that much more needs to be done. Federal coverage of long term care health care costs would go a long way towards a comprehensive national health care plan. OWL strongly supports such a national plan and recognizes the need for incremental change to attain that goal.

Recommendations for a Long Term Care Program

OWL believes that any legislation to provide long term care coverage to the chronically ill must include several key provisions.

1. The legislation must recognize the linkage between long term care and caregiving. We must not limit our discussion of adequate health care to the care recipient, but must realize that the caregiver, both unpaid and paid, is a vital link to the delivery of this care. Family caregivers need training, information, and respite. Family education and training should explicitly be included under services covered by any new program.
2. The program should ensure quality and access to care for all by providing better training, wages, and working conditions for paid long term care providers, such as nurses' aides and home health care aides. Many of these workers are earning minimum wage, with no health insurance or pension plan, and very little if any training. These conditions bear directly on the quality of care that can be provided.
3. The costs of a national long term care program should be spread as broadly as possible, through a social insurance financing mechanism as with Social Security.

4. The legislation must be intergenerational, providing services to all chronically ill regardless of age.

5. The services must be available to all who need them regardless of income. Eligibility should be based on functional, cognitive, or behavioral limitations, or the need for supervision, support, or training because of risk to safety or health.

6. The legislation must provide protection for low and moderate income persons from out-of-pocket costs. The program should pay providers directly, with no balance billing.

7. A broad array of home care services must be covered under the program and some services must be covered on an out-patient basis, to include other appropriate community settings.

Conclusion

Sen. Simon, the Older Women's League heartily supports your efforts to improve the health care coverage of millions of Americans. Everyday our country's families face the dilemma of providing quality care to a loved one. We look forward to working with you and your staff to enact in this Congress a long term care program that will provide these families with the help they so desperately need.



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TESTIMONY OF

THOMAS A. DUNCAN, JR., EXECUTIVE DIRECTOR

VAUGHAN CHAPTER PARALYZED VETERANS OF AMERICA ON BEHALF OF PARALYZED VETERANS OF AMERICA

MEMBER, ILLINOIS COALITION LONG TERM CARE

BEFORE THE

LABOR AND HUMAN RESOURCES COMMITTEE HEARING

ON

LONG TERM CARE

MARCH 13, 1989

Chairman Paul Simon, the Honorable Claude Pepper and members of the Labor and Human Resources Committee, I am Thomas A. Duncan, Jr., executive director of Vaughan Chapter Paralyzed Veterans of America, one of the 44 chapters and sub-chapters of National Paralyzed Veterans of America, a congressionally chartered veterans service organization. I would like to take this opportunity to thank you for affording me the privilege of appearing here today and submitting written testimony to this committee in regards to one of the most critical issues facing Americans of all ages -- the lack of a comprehensive long term care policy.

Sir, Paralyzed Veterans of America (PVA) has joined forces with the American Association of Retired Persons and more than 100 other health care, disability, religious and advocacy groups to promote a nationwide educational campaign on the need for a government policy for long term care protection. The cooperating organizations have a combined membership of over 60 million.

Member of: Combined Veterans Association of Illinois • Veterans Assistance Commission • Illinois Independent Living Center, Inc. • National Center for a Barrier Free Environment • Rehabilitation International USA • United Buying Service • Illinois Jobs For Vets • National Spinal Cord Injury Foundation • CTA Advisory Board Secretary of State Advisory Committee • Chicago Veterans Advisory Commission • Advisory Council for the Attorney General's Division on Disability

a paraplegic is an individual

The Paralyzed Veterans of America is a non profit organization dedicated to furthering the needs of the veteran, his dependent and all catastrophically disabled through service, education, medical research and the elimination of architectural barriers.

The question has arisen among many of the population and, indeed, among the members of this committee and leaders of this country as to why a veterans organization such as Paralyzed Veterans of America is advocating and speaking out on the need for long term care services to meet the needs of our elderly and catastrophically injured citizens? All members of Paralyzed Veterans of America have incurred spinal cord injury or dysfunction. In this regard, PVA maintains an active commitment not only to the nation's 25 million veterans, but to review and support the rights of all disabled Americans seeking fair and equal access to the provision of government and American society at large.

It is estimated that at least 1 million Americans each year become impoverished through the costs associated with long term illness and disabilities. Of this group, more than 2/3rds are elderly and a high percentage are children and disabled persons who are suffering from costly disorders or accidents, the effects of which last a lifetime.

All of our members have a need for some type and level of long term care. The major population of veterans, both young and old, have a need for long term care for the rest of their lives. Young disabled veterans would need services over an extended period of time and must be included in this national debate over long term care.

Long term care crosses many socio-economical segments of our society. It includes racial and ethnic groups, the elderly, religious denominations, organized labor, veterans and the entire population of America. The organizations representing all of these individuals have a combined membership of more than 60 million Americans. They are organizations that have performed countless studies and forums on the need for long term care in America.

To demonstrate our point, when we look at the demographics of the total aging population, projections show that the nation's long term care need grew for the ages of 65 and older with an increase from 11.3% in 1980 to 21.8% in 2050. This means that by 1990, there will be approximately 70 million people over the age of 65. The occupancy in the nursing home population for those aged 65 years or older will grow to approximately 2.5 million.

Compare this, sir, with the beginning of 1980 when most veterans of the World War II and Korean War eras turned 65. In 1980, there were 3 million veterans aged 65 or older. In 1990, there will be 7.2 million. By the mid-nineties, one third of all veterans will be over the age of 65, and by the year 2000, 9 million veterans will have reached this age group. As you know, as people age -- particularly as they age beyond 65 -- they require progressively more health care, and their need for long term care grows even more rapidly than their need for acute care.

There has been an increase in the use of VA in-patient hospital care. However, it is smaller compared to the statistics for nursing home care. Nursing home use by men 85 years and older is almost 30 times greater than the use by men aged 55 to 64. In 1985, approximately 140 thousand veterans aged 85 or older utilized the nursing home; from 75 to 84, 50 thousand; from 65 to 74, 20 thousand.

Comparatively, thousands upon thousands of veterans also need residential and nursing home care including room and board and other personal care supervision -- those who do not require hospital or nursing home care, but who, because of medical or psycho-socio health conditions are not able to live independently and have no suitable funds or resources to provide needed care. Yet the VA has not met these needs. Therefore, the veteran must seek a remedy from the private sector as all Americans must do.

Again, sir, we are not just talking about the aging population of the veterans nor are we just confining it to the overall aging population. There are many other people under the age of 65 who are disabled, chronically ill and/or in need of rehabilitative services. Most of these people are care for at home. Their long term care needs may be caused by a birth defect, rare disease, trauma or other catastrophic injuries. Approximately 40% of people who need personal assistance because of the inability to perform one or more activities of daily living are under age 65. Projections for the year 2000 show that 40% of functionally dependent Americans will be under 65 years old.

People under age 65 represent 11.3% of all nursing home admissions. A National Nursing Home Survey showed that each year there are about 146,000 nursing home admissions by people under 65. Inclusive in this population are the young disabled veterans who need personal care and services in the assistance of their daily activities, such as bathing, dressing, meal preparations, housekeeping and other health and chore-related tasks delivered by homemakers or personal care attendants.

Home care is the wider range of health and supportive services provided at home for people who require assistance in meeting their health and personal care needs. Services also include skilled nursing, physical therapy, occupational therapy and speech therapy which are delivered by registered and licensed practical nurses or therapists.

Another key provision necessary for long term care is the respite program. This service provides short term relief for family members who provide services to an elderly or disabled person at home. The service may be provided at home, at locations such as adult day care centers, or health care facilities.

The veterans organizations have submitted their alternative proposal, "The Need is Now, An Independent Budget by Veterans for Veterans' Program" and proposed all of these issues. However, as expenditures for domestic programs have been reduced in an effort to bring down the deficit, the VA along with other agencies, have experienced a "no-growth" budget in terms of constant dollars.

The issue now is whether or not the VA can continue to provide high quality medical care to veterans at the same time the numbers of aging and disabled veterans are reaching staggering proportions. If the Agency cannot, can veterans, many of whom are poor and uninsured, obtain health care in the non-VA sector?

Budget cuts have directly affected Medicare, Medicaid, community health programs, health professions education, medical research, and veterans' health care, among others. Yet with the population of uninsured, underinsured and uninsurable growing, the need for long term care is growing.

The VA is currently required to provide in-patient and out-patient care for veterans with service-connected disabilities, veterans in certain specific eligibility categories and veterans meeting certain strict income requirements who would otherwise not be able to afford or be eligible for alternatives to VA services. The Administration and Congress established new eligibility criteria for VA health care (Public Law 99-272) which sets these specific priorities for access to VA services.

The devastating consequences of this public law have the veterans in direct competition with the general population for public health care dollars and services. The VA, after meeting the needs of the veterans in the highest eligibility categories -- service-connected disabled veterans -- is the sole provider of care for a veteran population which is, by and large as stated before, underinsured, uninsured, uninsurable or medically indigent. As such, the VA, in most areas of the country, serves as a major safety net in providing care to those with few, if any, realistic alternative sources of care.

If VA resources are allowed to decline or require more stringent criteria, the result would not be the cost savings to the federal government, but a cost shift from the VA to other federal, state, local or private health care providers who are in no position to accept the patient demand or the increasing demand for financial resources.

Long term care is indeed expensive. The average annual cost of nursing home care was \$22,000 in 1985, and is about \$26,000 in 1988. Costs are much higher in many places. In Washington, D. C., for example, the annual nursing home charges for Medicaid reimbursed bills range from \$36,000 to \$48,000, or \$99 to \$132 per day. Intensive home health care is expensive. In 1988, the average home health care visit reimbursed by Medicare cost \$63.00.

The high cost of long term care has led and will continue to lead Americans to poverty unless we realize that long term care services should be available to all individuals regardless of age or income. Net worth should be based on functional, cognitive or behavioral limitations or the need for supervision because of risk to safety or health or the need for support or training.

It's ironic that under America's health system, once a person becomes so desperately ill that there is no hope of him or her being self-sufficient, Medicare and most private insurance coverage comes to an end and the patient and his or her family are left to fend for themselves. Life savings can quickly be depleted from costs associated with long term care that their only option is to spend down to poverty in order to qualify for Medicaid. The average allowable assets under Medicare are \$3,000 for a couple and \$2,500 for an individual.

Many of our veterans are non-service connected, which means they were not injured during a war time period and are therefore not afforded the same benefits from the Veterans Administration in terms of extended care. Many did not serve during a war time period and are subject to use either Medicare, Social Security Income or Medicaid.

This most significant gap in the division of health care today in regards to long term care solidifies the fact that this nation's health care system, as a whole, is totally unprepared to meet the long term health care needs of an unprecedented number of older veterans, senior Americans, disabled young adults and children and certainly cannot be found in the present federal safety net program of Medicaid nor in the private sector.

PVA strongly contends that the government must address these needs. Government is not the only answer to long term care or the only solution to the problem. But government is the only entity that can establish the policy and the direction to find that solution. It is a problem, we believe, that must be emphatically addressed by the policymakers, politicians and the men and women who are currently leading this nation and who will lead us in the coming years.

Corroborating polls conducted during the Presidential Primaries this year by Long Term Care '88 confirmed that 82% of all American families from all income levels and geographic locations believe that the cost of long term care for catastrophic conditions is a major problem facing our nation. Support for a government program is overwhelming across age groups, income levels and political ties. By a 5 to 2 margin, many Americans show a willingness to tax themselves at rates that correspond to their income to pay for long term care. More than 8 out of 10 Americans believe that long term care coverage should not just be for the elderly but for disabled individuals of all ages.

In this country, no American should have to live with the fear of financial disaster in order to provide long term care for themselves, their children or their parents. They should not have to be asked to become impoverished in order to receive federal assistance for long term care for their loved ones.

Parents of medically dependent or mentally ill children find minimal financial relief from private insurance policies. Frequently policies are terminated and families join the ranks of the nation's uninsurable. Working, middle class Americans are not only struggling to keep their mortgages and send their children to school, but are increasingly faced with the financial and moral responsibilities of providing for the long term care of their parents.

I cannot overemphasize that the equal rights of the disabled and handicapped individuals should include equal access to health care services for all Americans of any age. The long term economical and social consequences of a disability can be just as devastating for a grandfather with Alzheimer disease as a grandson with multiple sclerosis. The impact and cost of disability can affect every generation within that family. The emotional, psychological and financial cost of long term care forces families of loved ones to make major sacrifices.

In conclusion, sir, many individuals here today have testified both orally and with written testimony on the devastating impact on Americans regarding long term care and the need for governmental intervention. Medicare provides some assistance, Medicaid provides some assistance, private insurance provides some assistance to long term care.

Current catastrophic health care initiatives for Medicare provide significant improvements in coverage of acute care, but primarily for those over age 65. Eighty percent of true catastrophic health care expenses are for long term care provided outside a hospital.

We are one of two nations that has not addressed the long term care issue. South Africa is the other.

Long term care will benefit not only those over 65, but those that are younger, in many ways. We must look at some alternatives. There have been many proposals by several congressmen, including yourself, sir.

We must find a way to fundamentally establish a national long term care program. Whenever we mention an increase in taxes, everyone seems to shy away or look at you as if you have spoken a dirty word. For Americans to enjoy life, liberty and the pursuit of happiness, it must also include quality delivery of medical care both institutional and non-institutional.

People are willing to pay for the service. In terms of reducing the budget deficit, we must look for and prioritize funds to some of the most needed life support programs such as long term care. We have to look at a tobacco tax and estate tax, since the heirs of people over 65 will pay the taxes. Many of the young adults polled by PVA and AARP demonstrate that people under 65 would pay some type of payroll tax, alcohol and gas excise taxes and even income tax surcharges. The minimum amount would be taxed to people over age 65.

This is not a conclusive answer to the issue of long term care. But the individuals here today have demonstrated that there must be a solution to this crisis facing America. Vaughan Chapter Paralyzed Veterans of America and the Illinois Coalition of Long Term Care strongly encourage this committee to address the need for a governmental policy of social insurance to provide long term care. Both Vaughan Chapter PVA and the Illinois Coalition for Long Term Care support a long term program which will be completely inter-generational catastrophic coverage provided for Americans of all ages. Failure to do so will condemn the elderly, the disabled and their families to a dismal future of desecration, deprivation, poverty and the right to life, liberty and the pursuit of happiness guaranteed by the Constitution of this United States of America.

I want to thank you, Mr. Chairman, and your committee for giving us the opportunity to submit this written testimony and be present here today to hear all issues of concern regarding long term care. We hope that this testimony has projected to the committee and all those who will read it, the concerns of Paralyzed Veterans of America and veterans who make up an integral part of this society and are concerned about the future of the elderly and disabled Americans.

PREPARED STATEMENT OF JOANNE G. SCHWARTZBERG

I have been asked to provide you with a physician's view of home health care. My angle of vision arises from 17 years as Medical Director of Home Health Service of Chicago North. I am a Clinical Assistant Professor of Preventive Medicine and Community Health at the University of Illinois, and am a founding member of the Board of Directors of the Chicago Geriatrics Society, a professional organization of physicians concerned with the medical care of the elderly.

We are all aware that one of the fastest growing portions of the American population is composed of those over 65. We also know that the great majority of elderly people consider themselves in reasonably good health and function as active, independent members of the community.

At any point in time, approximately 5% of those over 65 are in nursing homes. Another 14% are cared for at home. They are generally homebound due to the effect of multiple chronic conditions and are at high risk of developing acute medical problems necessitating hospitalization and/or intensive home health services.

Thus, it helps to think that for every impaired elderly

person in a nursing home, there are 3 more cared for in their own homes.

More than 85% of the care provided for the "frail elderly" in their own homes comes from the informal support systems of families and friends. Only 15% comes through community resources.

When we look at the financial side, only 3% of the total Medicare budget goes to home health services, such a small amount, it can be easily over-looked in governmental health planning. Yet that 3% provides very significant services to a large number of patients and indeed, often makes it possible to prevent nursing home placement as well as to shorten hospital stays and prevent rehospitalization.

"There is no place like home"; over 80% of the elderly preferred home care to nursing home care in a recent study by the University of Minnesota. Physicians have long observed that motivation is an important part of recuperation and healing, even wounds appear to heal more quickly at home.

Medicare coverage of the home care needs of the elderly has been based on an acute care model and an unsound definition of medical necessity.

From the physician's point of view, the goal of providing medical care is to maintain the patient at the highest level of functioning, to achieve the best control of his disease processes and maintain that control by providing whatever services are necessary. This is the basic philosophy under which most physicians practice medicine.

Medicare, on the other hand, has taken the physician's goal of maintenance of good health and turned it upside down. The bureaucratic mind has deemed that it is not "medically reasonable and necessary" to provide "maintenance level care." Thus, just as the physician begins to achieve the goal he has set for the patient, Medicare denies further care. Medicare not only denies reimbursement for further care, it states that such care is wrong, that the physicians goals and plans are "not medically reasonable and necessary."

In the quixotic world of Medicare you have to constantly get sicker in order to qualify to receive care. You can't come too close to being cured.

A physician used to look at a patient's illness and the required services from the hospital necessary to maintain that patient and prevent further deterioration and he would write on

the chart that the patient was stabilizing--meaning that the patient was receiving the care that met his needs and his condition was not deteriorating and had the potential of improving. Nowadays administrators make sure that physicians don't use that useful term because if Medicare sees the word "stabilizing" they will deny care at that level, whether it is at the I.C.U., the stepdown unit, the intermediate care unit, the skilled nursing facility or home care.

This is a Kafka-esque situation for physicians. By redefining medical terms to mean the opposite of what they have always meant, Medicare has left physicians tongue-tied.

The greatest bastardization of the language has come in the bureaucratic use of the term "medically reasonable and necessary." This is the term that claims reviewers use in order to cut costs without having to change the wording of the regulations. The physician orders the care he thinks necessary for the patient, the home health agency provides the care ordered by the physician and covered by the regulations, and then HCFA denies payment on the grounds that it was not "medically reasonable and necessary" because the patient didn't get worse. The care provided prevented the patient from getting worse, but since his condition has not changed, there is no proof. Without proof, documenting either a negative or a positive change, care is

denied as not "medically reasonable and necessary."

For example, ill patients need supportive care, they need help with a bed bath or a shampoo or shave, someone to prepare a light meal, straighten the bed and standby to support the patient as they take their first unsteady steps. The person who provides this care in the home is the home health aide.

The Federal regulations describe home health aide services in detail. "Home health aide visits usually last 1-3 hours a day and generally are provided 2 or 3 times a week. These figures are intended to be used as guidelines, not as limits in the coverage of aide services, since there are cases where longer and/or more frequent home health aide services would be reasonable and necessary (example, for a recent diabetic amputee who needs intensive personal care services). Accordingly, where these norms are exceeded, the agency must furnish documentation justifying the need for additional services. Where the need is justified, payment should be made."

That seems very clear, the norm stated is an aide 2 or 3 times a week, however in Illinois we can only put an aide in the home one time a week unless the patient is completely bedbound and incontinent or has an open bedsore. Even in 90 degree weather in the summer, a severe cardiac patient on continuous

oxygen, barely able to get out of bed briefly 2 or 3 times a day, cannot get a bed bath more than one time a week until his skin has broken down with open sores and then the aide can go in 2-3 times a week until the sores have healed. If the agency attempts to put an aide in 2-3 times a week from the start to prevent the development of bedsores, the service will be denied as "not medically reasonable and necessary." The regulations state the norm as 2-3 times a week, the home health nurses know that 2-3 times a week is a minimum to prevent the development of bedsores; but if no sores develop, there is no proof that the care was needed, and the reimbursement will be denied. These denials, under the guise of not "medically reasonable and necessary" make a mockery of quality medical care.

These home health aide services can only be provided while the patient is ill enough to require skilled nursing care. Once their condition is medically stable, no further home health care can be provided in most circumstances. Many patients require only short-term home care to enable them to recuperate from serious illnesses and are then able to manage their lives independently. However, the "frail elderly" who are unable to manage some of the activities of daily living such as eating, dressing, bathing, toileting and walking without assistance have long-term home care needs that are rarely covered by Medicare.

The few exceptions when Medicare provides minimal long-term care coverage come in those instances when the patient's condition requires continuing skilled nursing intervention--for example, to provide monthly changes of a urinary catheter for a bed-bound, incontinent patient.

I would like to tell you about Mrs. P., age 75, completely bedridden with multiple health problems including heart failure, high blood pressure, diabetes, paralysis of the lower extremities, and urinary incontinence. She lived in her own home and was responsible for 4 teenage grandchildren, ages 13, 15, 16 and 18. The mother was dead and the father permanently institutionalized with severe brain damage. Mrs. P. refused to consider a nursing home because the grandchildren would have been separated and placed in foster homes. She ruled the household from her bed.

She had been frequently hospitalized and was referred to home health services after confusing two of her heart medicines that appeared the same size and color and overdosing on Digitalis. The home health nurse worked with her to establish a schedule and system she could follow. But alone all day, while the grandchildren were in school, she easily forgot to open the envelopes or empty the egg crate section at the right time.

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The home health nurse drew blood for lab tests that proved that the patient was not getting the proper dosages, but renewed exhortations led to no improvement. She was hospitalized again with a drug-resistant infection (because she hadn't properly taken the antibiotic prescribed earlier), and returned home with still no solution to the problem. She knew it had to be solved if she wanted to remain home in control of her family, but she kept forgetting. The grandchildren were in school all day and unable to help.

Finally, one of the nurses had a new plan. She had noted that the patient spent every day watching television and because she could not get out of bed, she watched one channel only. So the nurse made up a huge sign to rest on top of the TV set, clearly seen from the bed. On it, in large print, she wrote out the names of the television shows that the patient would be watching and drew large pictures of the pills to be taken while that show was on. "As the World Turns" followed by a large red pill, a large white pill, a small white pill, etc.

The system worked, her condition stabilized and she eventually required the home health nurse only once a month to change her urinary catheter and once a TV season, to change the sign for the new shows.

Mrs. P. stayed at home and watched over her grandchildren for over 3 more years. She saw three of them graduate from high school and her oldest grandchild married before Mrs. P. died, at home.

Mrs. P. received long term home health services as an exception to the usual Medicare coverage. Although she was chronically ill, her condition was stable requiring maintenance level care (a nurse once a month, an aide once a week), which is not covered. However, because she needed a urinary catheter which had to be changed once a month and required a skilled nurse to change it, the service could be covered by Medicare under the skilled nursing rule. Because she required skilled nursing service all of her maintenance care needs could be covered by Medicare. If she had been bedbound because of a different disease, such as Parkinson's, or multiple sclerosis, or following a stroke, and had not needed a catheter, her care would not have been covered by Medicare.

For these unfortunate bedbound patients, Medical care is episodic and very expensive. They don't receive proper maintenance care at home (either there is no family or the family cannot provide it) and so their condition deteriorates. They develop bedsores, become septic and are admitted to the hospital. With expensive treatment they recover, come back home, receive

brief home health services until their condition stabilizes and Medicare benefits are cut off. Then they are left on their own, and the cycle repeats over and over and over.

The cost of care for Mrs. P. ran about \$285/month or \$3,400/year. Her frequent hospitalizations before she ever received home health care cost between \$3-10,000 each. Her least expensive hospitalization would have paid for her home health care for a year.

If Mrs. P. had not received home health services and had continued to be frequently hospitalized, she would have ended up in a nursing home at a cost of \$20,000/year, paid for by the State under Medicaid. In addition, the 4 children would have had to be placed in foster homes at considerable long term expense to the State. So as a matter of social policy, a minimal investment in long term home health care can reap significant savings in acute health care costs as well as other social welfare costs.

But we do not have long term care coverage under Medicare either for home health care or for nursing home care. We urge the Congress of the United States to consider extending Medicare benefits to cover maintenance level and preventive care for the "frail elderly" in their own homes and, when necessary, in institutions.

CHICAGO ADVISORY COUNCIL ON AGING
and
CHICAGO ADVISORY COUNCIL ON DISABILITY

JOINT RESOLUTION FOR LONG TERM CARE

WHEREAS, national healthcare costs are escalating at a faster rate than citizens can bear, and

WHEREAS, there are more persons that are being treated for chronic illnesses than in past decades, and

WHEREAS, there is a lack of comprehensive long-term care coverage to pay for services, and

WHEREAS, all Americans may need long-term care services at some point in their lives,

THEREFORE, be it resolved that the Chicago Advisory Council on Aging and the Chicago Advisory Council on Disability recognize the need for a federal long-term care program, and recommend passage of legislation in accordance with the following principles:

1. Eligibility: Persons who are unable to perform two activities of daily living as defined by the Health Care Finance Administration or who have cognitive impairments. Persons will enroll in the program on a voluntary basis. Periodic reviews of participants will be required.

2. Services Offered:

Day Care will be provided up to a maximum of seven days a week at 100% coverage with no deductible for enrollees. The maximum years of service ~~will be~~ based on need.

Certified In-Home Respite Care will be provided for up to 30 days each year, to be taken on either an hourly or per day basis determined by the caregiver.

Housekeeping and Personal Care will be provided up to a maximum of seven days a week at 100% of coverage with no deductible for as long as the client requires assistance.

Skilled Nursing, Intermediate or Custodial Care Facility services will be provided with full coverage for up to five months. In the sixth month, a co-payment will be required. A Spouse's Impoverishment Law, similar to the State of Illinois law, should be instituted nationwide which would enable the spouse to keep 50% of the liquid assets, a house and a car.

Home Health Care service will be provided by a Certified Nurses Aide, Licensed Practical Nurse and Registered Nurse on an as-needed basis.

Hospice Care will be provided to individuals who are terminally ill, including those not eligible for Medicare-funded hospice services, on an as-needed basis. This should include persons with Alzheimer's Disease and AIDS.

3. Administration of Program:

The U.S. Department of Health and Human Services (HHS) should administer the program. HHS should promulgate regulations regarding procedures to implement the bill within 180 days after passage of a long-term care bill. (We recommend input from the Social Security Administration, Administration on Aging, and the Rehabilitation Services Administration.)

States will be required to have their own Long-Term Care agency which will receive funds for the program and allocate those funds to the following state agencies responsible for:

- rehabilitation
- aging
- public health
- mental health
- developmental disabilities
- children and family services
- insurance

A team consisting of at least a social worker and registered nurse should make an assessment of the client's needs within 30 days of the request. Case workers must provide and explain a bill of rights to the client that the client can understand. If the client is denied services or feels services should increase, there will be an appeal procedure.

Daily operation of the program will be divided as follows:

- 0 - 59 years old - Rehabilitation services
- 60 years and older - Aging Agency

4. Sources of Funds:

The federal government should provide for the program through General Revenue funds. Funds in the federal budget should be allocated for long-term care.

We believe funds can be increased by:

- A) Eliminating the cap contributed to the Medicare Trust Fund by persons with higher incomes. This money could be designated for the Long-Term Care Program.
- B) Establishing a national Long-Term Care Facility Insurance Program that persons can voluntarily purchase in advance to help defer the cost of the co-payment beginning in the sixth month.
- C) Increasing federal taxes on tobacco and liquor industries to support the program.
- D) Initiating a federal lottery. Proceeds will help fund a Long-Term Care Program.

All collected funds will go to a Trust Fund from which the government cannot borrow to pay for the deficit.

We are opposed to increased premiums to recipients on fixed incomes.

COMMENTS

We recommend increased funding for research on conditions that create a need for long-term care.

In regards to the allocation of funds, on an average, it costs \$24,000 per year to provide nursing home care versus \$12,000 per year to provide in-home care. If nursing home placement is prevented due to the provision of in-home services, the money saved by the government in the Medicaid program should go to the Long-Term Care Program to help pay for additional services.

LONG TERM CARE FORUM
United States Senate
Senator Paul Simon

OPENING REMARKS

C. Jean Blaser, Ph.D.
Manager, Community Care Program
Illinois Department on Aging

Thank you for the opportunity to participate in this discussion of an issue whose "time has come". Long Term Care is an issue which will only grow, and with its growth comes challenge and opportunity.

My name is Jean Blaser, and I manage the Community Care Program for the State of Illinois. The Community Care Program is a program of in-home services to prevent or delay unnecessary nursing home placement; and offers case management, nursing home pre-screening, chore-housekeeping, homemaker and adult day care on a statewide basis. The program is large: We serve over 27,000 persons each month. In fact, the Community Care Program is one of the largest programs of its kind in the country.

The Community Care Program is an entitlement program. Since 1983, any person in need of home care, and who met eligibility requirements, has been able to receive the services in a timely manner.

The Community Care Program is cost-effective. Since 1983, all new growth in long term care clients has been to home care. No more clients are in nursing homes in Illinois in 1988 than were in 1983. Because costs of home care are about 1/3 the cost of institutional care, the Community Care Program has saved Illinois and the Federal budget millions of dollars. This year alone, we estimate the cost of providing nursing home care, rather than community care, would be over \$250 million. If all these clients were Medicaid eligible, the Federal cost would be \$125 million, compared to the \$12.7 million cost of the 2176 waiver. That is a ten-fold savings to the Federal Government.

I have provided this brief background of the Community Care Program, in order to form the basis for my recommendations for future directions as we strive to develop a national policy on long term care. Any policy should draw upon the experience of states like Illinois, with large programs of home and community services. From this experience, we have learned the following lessons.

1. Home and community-based care should be the preferred option. Older persons and their families prefer home and community-based care; and it can be much less costly. Any policy that focuses solely on nursing home care is doomed to failures -both because of client preference and overall cost.

2. The Federal government should work in partnership with States to develop and manage and fund these services. There are many reasons why the Federal Government should look to States as partners in these services.
 - A. Many States already have working systems in place such as Illinois' Community Care Program. To disrupt these systems is costly, and will meet with great resistance.
 - B. These States have considerable experience and expertise in developing and managing cost-effective programs. Most of these programs are largely state-funded and, so, the managers are fiscally conservative.
 - C. States make a financial commitment to home and community-based services. Illinois, for example, contribute 85% of the cost of the Community Care Program.
 - D. Major experiments and innovations have come from states. Foster care, assessment tools, care for Alzheimer's victims all originated at the State level.
 - E. Need for local flexibility - what works in Southern Illinois does not work in Chicago, and certainly can not be readily adapted to Oregon or New York or Mississippi.
3. Clients should share in the cost of their care. While the amount of the cost share does not have to be substantial, and should be based on ability to pay, our experience has shown that cost sharing:
 - * limits over-utilization
 - * insures client participation in the care - one of the most damning comments I have heard is the client who said, "Well, I guess my worker is ok. I certainly wouldn't pay her for her work, but the State does."
4. Case management is a critical component of the service system. Case managers assure equal access, assure the care plan is adequate, and provide essential follow-up and monitoring. They offer the client a contact when the service isn't working. However, case managers should not also be the provide of the in-home service, since this creates a serious conflict of interest.

I am sure, as the discussion progresses, I will have other recommendations to offer, but these four are most critical and I thank you for the opportunity to offer them for your consideration.

PREPARED STATEMENT OF JUNE PONIATOWSKI

January 1989

RE: June Poniatowski - Alzheimers Care at Home and in
Nursing Homes

When I realized that I needed someone to help Mom during the day, someone suggested Southwest Case Management (see file).

After the initial interview, I had to wait for the case to be investigated and a worker to come. They would provide 4 hours a day.

The workers from Southwest Case Management (through various vendors) are paid minimum wage, and are not trained to, and could not, cope with Alzheimer victims. Many days no one would show up. I called the vendor and all they could say was they didn't know what happened. I would be at work wondering what was happening.

Mom did not want anyone in her home telling her what to do (especially black workers - she was 72 and grew up in an era and area where there were not many blacks in her life). There was nothing I could do about that - as I told Southwest Case Management many times.

Mom was assigned a good worker (older, compassionate, patient, white) named Wilma Jenkins. She got Mom to cooperate with her, and they got along fine. Wilma got sick, and Mom did not do well with the substitute workers. It was O.K. when Wilma returned.

Then, after I requested more hours, Southwest Case Management suggested that Mom go to day care center so that the hours for the worker could be used for the other three days.

I had a hell of a time with the negotiations for the day care center. All the day care centers were on the East side, and I knew she wouldn't stay in those. There was one in Cicero/Berwyn. I would have to take her there and pick her up after work. They did have a bus, but because Mom lived two blocks too far into Chicago she could not be picked up!!! I also had to wait for special dispensation from Springfield before she could go to that day care center, etc., etc., etc.

Mom, because of her disease, just did not want to be away from her home and would not go to the center. I have since talked to a woman with ADRDA, Nita, who said her mother did not want to be at day care either, but she is fortunate enough to have the money to get enough help.

I then requested that the worker come back 5 days a week, and requested Wilma again. I had another long battle on my hands to try and get Wilma back. (That would take another four pages to document.)

ALZHEIMERS
Poniatowski, J.

(2)

In one instance, Mom had to go over to the neighbors and ask him to come over and change the t.v. channel - as the worker was asleep at the dining room table. (I had just gotten her a new, remote control 19" television, hoping to interest her in a lot of t.v. I didn't know then that I shouldn't have changed anything, so that she would have nothing else new to cope with besides workers in her home!).

She also tried to throw one worker out because she splashed a whole bucket of water (about 1 inch deep all over) on the kitchen floor to wash it, and Mom knew that wasn't right and was very angry. (The worker I had hired to come in the rest of the day was already there, and she was the one that said it was about 1 inch deep).

The case worker came out again, after Mom hit one of the workers. They would send 2 workers 2 hours a day (instead of one for 4 hours), for own their safety.

Mom still would not let them in. The case worker came out again, asked Mom a lot of questions, asked me how many hours a day I had help in the house for her, etc., etc., etc. I told them I was doing the best I could do, coming every night, cooking, putting her in her nightclothes, etc., and being there all weekend. I asked why couldn't they give me more help?

I got a phone call, at work, a few days later saying that they were going to place the case with the Protective Custody Department because I did not have 24 hour care for Mom. (See letter from Dr. Vanderberg)

The very agencies you go to for help create many, many more problems than you had to begin with!

I then had no choice but to place Mom in an institution.

I did not know where to start. No one has any guidance other than just look at them and decide.

I placed Mom in West Suburban Home for the Elderly. I did not find out how dirty this place was until I went in to put things in the room for her. (That is the whole trouble, you really don't find out about these places when they are giving you the "quick" tour until you have signed the ludicrous contract and have your loved one in these places.) I had to scrub the flagstone on one wall of the room she was to have in order to clean it up enough so that she could live there. I asked to have the room painted, which was done. I found out later that it was painted by the nurses aid.

ALZHEIMERS
Poniatowski, J.

(3)

Mom was very, very upset and did not want to go into the place. She was hanging onto the car. A nurse and an aid came out, restrained her, and told me just to leave her screaming in the drive way and go. That was the hardest thing in the world I have ever done, and I am still upset when I picture that moment. I find now, through experience, that I should have never listened to them. I should have gone inside with Mom, stayed with her all day, and comforted her so she would have someone other than strange people around, keeping her in a strange place she did not want to be in. She has asked every time, since I have placed her in two other facilities, if I am going to just leave her. I have not, and will not ever do that again. She still remembers being abandoned in a strange place, with rough strangers keeping her in what must have seemed like a nightmare to her.

As time went on, I complained about no toilet paper/dispenser, or paper towels/dispenser in the washroom she was to use (it was through the dining room and in the hall - which I didn't realize would be very confusing and difficult for her). I was told there was a lady that took the toilet paper so they didn't put any in there. No explanation for no paper towels or soap.

One Saturday I had just come to visit, and Mom cried every time I touched her arm. I took her sweater off and found her whole arm bruised and scraped. I took her to Christ Hospital Emergency Room, they X-ray, thought she had a hair-line fracture, and put her in an arm sling. When I got back to the place, I asked the nurse on duty (and many people after that) why they did not take her sweater off. I was told that she only complained about her shoulder - not her arm. I stated that they knew she was an Alzheimer victim, why didn't check her whole body if she was crying. The administrator keep saying she just complained about her shoulder. The nurse did say that she burst out crying in the afternoon and she had her lay down on the bed. Again, no one thought to take her sweater off. The nurse said she should have, but didn't!

I then filed a complaint with the Nursing Home Hot Line about the cleanliness and care. It seemed to me that after I had filed the complaint they started to clean the place up a little - vacuuming, washing down banisters, etc., etc., etc.

In the six months that she was at West Suburban I had to take her to Christ Hospital Emergency Room at least 4 times. (For further details, please contact Dr. Vanderberg)

After getting the report back that they had no "violations" I was fed up and decided to move Mom. I asked everyone I knew, including nurses, what home they would recommend. No one had a loved one in a home. Some had visited homes, but didn't have anyone in one. Again, I was on my own to look them over and decide.

ALZHEIMERS
Poniatowski, J.

(4)

A friend recommended Concord Nursing Home. I placed Mom there in January.

I did not feel she got the care she should have had at this facility either. (See enclosed file) Again, they were not able to care for Alzheimer victims!

They lost Mom's hearing aid at Concord. I was told "they are not responsible for it". The Legal Ombudsman for Cook County wrote them a letter that they were responsible. A lot of good that did! So, she then did not have a hearing aid!

Concord did not have any air conditioning in the rooms on her wing, and the hall duct did not work properly. The nurses told me that they had complained how hot it was on that section. Mom is very territorial and always closed the door to her room. I came in on Saturday in July and found Mom in a restraining chair with tray. I took one look at her and new something was very wrong.

They said they had taken blood for a Haldol level, because something was wrong. I asked why she was in the chair, and they told me "so she doesn't fall down". I felt her head and she was burning up. I had to lock my arms around her and to lift her out of the chair. She could not move, could not lift her head up, and could barely talk. I told an aid to help me and we took her into her room to the bathroom. I put her on the toilet, wiped her off with cool wash clothes, and gave her water to drink. She drank 8 glasses of water!!!

I decided to move her again because of the lack of concern and care. I didn't want to do it because it is very bad for an Alzheimer victim to keep moving, but I didn't want to come in one day and find her dead from negligence, either.

I had been looking at Brentwood for sometime. I contacted the Legal Ombudsman again. I told her I would like to place her in Brentwood, but wanted to make sure they took Medicaid, because my money was running out. (See attached letter)

I had been told (by Cook County Legal Ombudsman for Nursing Homes) not to mention Medicaid to Brentwood - just put her in there and tell them later she had to go on it. The day I placed Mom in Brentwood, the contract I signed said they did not take Medicaid! I never, never would have placed her there if I hadn't gotten assurances (Legal Ombudsman and Congressman Russo's office (Pat)) that they did take Medicaid. Mom got good care in the section she was in at Brentwood. It was very, very hard on her to move again.

ALZHEIMERS
Poniatowski, J.

(5)

I filed for public aid for her on July 29, 1988. It is very hard to find even a fair quality nursing home when you are public aid pending!!!!

The one facility recommended by Ms. Dempsey at Public Aid was Bridgeview, at 8100 S. Harlem. I applied there and was told that I would have to pay \$3,400 up front as a deposit because public aid is so slow with claims and payment. Mrs. Berna said that they had a room on the 4th floor.

I was in a desperate situation. I had to get her out of Brentwood because I could no longer pay, and there were few places to choose from. I applied for and got a loan at my credit union for the money. I called Mrs. Berna and told her that I would have to talk to my lawyer about signing the contract because she had stressed that I would be responsible until the time public aid paid (not until the time she got a public aid number, but the time they PAID).

One of the nice aids at Brentwood (Clara), who had taken care of Mom almost every day, asked where she was going. I told her and she said that she had worked there before. I then told her she was going to be on the 4th floor, and she said, "On, No, you don't want her on that floor". I went to Bridgeview on Saturday and Sunday, August 5 & 6. I went up on the 4th floor. What a mess. Not one person was ambulatory. They were all in wheelchairs or restraining chairs. Three or four were screaming constantly. I was told, later, that when Manteno closed some of the patients were put on the 4th floor at Bridgeview.

This certainly was not a floor I wanted my Mother on. I went down on Sunday to talk to the administrator, Mr. Dudec. Once in his office I told him that I would like to express some concerns about Mom being on that floor as she was completely ambulatory, etc., and didn't want her with psychotic patients from Manteno. He interrupted me and said that he would like to express his concerns! He did not like me "throwing around" Ms. Dempsey and Congressman Russo's names, did not like it that I wanted to talk to my lawyer before I signed their contract, and that they would "do what they wanted, when they wanted, and to whom they wanted", and if I didn't like it I could have my deposit back and "GO TO GREENTREE"! (Greentree is one of the worst nursing homes in the area, and everyone knows it.) He knew that I was in a desperate situation and could not do anything but accept his meanness and place Mom on 4. I constantly asked, and Dr. Vanderberg (our doctor) asked, that Mom be placed on the 3rd floor ASAP. All they keep telling us was that "there is a waiting list with 2 more people ahead of her". The patients on 3rd floor told me that there were two or more beds open on 3. (As of September 1, three new people came in from the outside and were placed on the third floor).

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Mom was only at Bridgeview from August 8th until she was put in the hospital (Christ Hospital, Oak Lawn) on September 2, but in that time they lost her upper denture (they said they were not at all responsible for things like that) and beat her up.

I went to visit her every night after work, because I was afraid not to because of the floor she was on.

I went on Thursday night, August 25, 1988 and she looked o.k., I went back on Friday night, August 26 and she was crying, and crying. I saw that her left arm had gouge marks (2) with blood blisters underneath and a bruise under her nose. When I checked her hands, she cried when I bent the fingers of her left hand back. The next day, Saturday, August 26, I found bruises on both breasts and scratch marks on her right breast. As a few days passed, the bruising got more and more pronounced on her breasts and on her upper right and left arms and on the fingers of her left hand.

I talked to the head nurse on duty on Friday night, August 26, and requested this be noted in the chart. I also called the Director of Nursing on Monday morning, August 29 and asked if they could explain what happened. She had her assistant, Subash, examine Mom. He called me back and said that she had a lot of spider veins, a lot of spider veins. He kept saying that. I said that had nothing to do with her bruises and scratches, and wanted to know what had happened. He said that she probably had an encounter with another patient. I told him that it was very unlikely because no one but one other woman was ambulatory on that floor. I was also terrified that she might have been, or was being sexually assaulted.

Mom was now without her hearing aid, without her upper teeth, and in the hospital from being brutalized.

Mom was in Christ Hospital from September 2, 1988 until September 17, 1988. During her stay, I told the social worker that I did not want to place Mom in another nursing home without an Alzheimer's unit. The social worker could not find a public aid nursing home, in our area so that I could visit her, that had an Alzheimer's unit.

The hospital was demanding that Mom be discharged. I had no other choice but to put her in another nursing home WITHOUT an Alzheimer's unit.

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I placed Mom in Oak Lawn Convalescent Home on September 17, 1988. From the start, both Dr. Vanderberg and I have asked that Mom be put in a semi-private or private room because of the Alzheimer's she is very territorial about her possessions and her room. So far, she has only gone from a 4-bed room to a 3-bed room.

When I came in every night, (she was in 208-4 then, she is now in 213-1) her bed would be wet. I would tell the nurse and sometimes the aid about it all the time. I changed it every night. I wouldn't let an animal sleep in a wet bed, let alone my own Mother.

Because they couldn't seem to accomplish the task of taking Mom to the bathroom when she needed to go or every 2 hours, and she would go through 3 - 4 outfits a day (I do the wash because she only has 5 outfits and I cannot afford to keep replacing clothes that are lost (so far, two full and 2 half-pairs of pajamas have been lost) - one resident on the first floor lost 6 pairs of nice slacks - and the smock tops Mom likes are very hard to find), I coaxed her into wearing an undergarment (she knew what diapers were and wanted no part of them - they were "for babies").

I (and also Dr. Vanderberg) have asked, and complained, and asked that she be changed whenever her undergarment was wet, or at the least every 2 hours. She just hates to be wet or soiled, as she is a very neat and clean about herself. In November I came in (I go every night to make sure she is somewhat o.k.) and she was soaked through again (undergarment, panties, slacks, and another pair of slacks she had apparently put on because everything was wet!). I was furious. I changed her, and then took the clothing down to the Director of Nurses, whom I had seen when I came in. I showed her all of the soaked clothing. She said "I'll see about it". Other times I have come in and she was soaking and full of excrement (the undergarment, panties, and slacks were full of it where it has oozed out of the undergarment. I came in on Christmas Day and Mom had no undergarment on, no panties, and her slacks were wet from the ankle up. I am still fighting this battle.

Mom had been very upset every night I came in. I finally found out from other residents and the aids that the day people were taking her animals (that is her security when I am not there) from her and teasing her with them in order to get her to do what they wanted. They were also taking her watch off and teasing her with it to get her to do what they wanted. I found it broken in her drawer. These are her only possessions (she has said to me "don't have anything, everything gone") all of which she knows are hers, and it makes her very angry for them to do this to her. I confronted the supposedly professional Assistant Director of Nursing with the information about them teasing her, and her

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reply was "what else do you suggest we do?" !!!!! I told her that you have to talk to my mother (she has told me more than once "nobody talks me, nobody listens"), smile at her (as she intently watches everyone's facial expressions), ask her permission to do something to her, and get her cooperation, and not upset her so. Then the ADON said, "well, she eventually calms down."!!!

Mom is very afraid of water and being undressed (I don't know if it has a lot to do with her beating or is just the Alzheimer's). I thought right away that she wouldn't like her hair washed with the water dripping in her face, and told them I would wash her hair on Saturday, as it would be less upsetting for her and stem a problem for them if I did it. I tried to find a place that I could do it in, and found a high bath tub she could lean over on the first floor. I requested of the Administrator that I be able to use the beauty shop, as it would be more comfortable for Mom. He said we can't do that, because there are chemicals there that she might get into (I told him I would be with her at all times, and would be willing to pay a small fee for the weekly use of the room, if the hairdresser objected), and he would have to look into it. I am still washing her hair over the tub.

About a month after she was first in this home, I asked, more than once, the aids to give Mom a bath instead of a shower, because it wasn't quite as frightening as a shower. I suspected they were still giving her showers, so I called the DON and asked that Mom be given a bath instead of a shower, because she was afraid. The DON stated that it was easier for them to give Mom a shower than a bath. I again requested, of the DON, that she be given a bath. I have since told them I would give her the bath on Saturday when I wash her hair.

In November Mom had a broken wrist. I came that day and found her hand red, swollen and hot, and she wouldn't use her hand for anything because she said it hurt. I told one of the nurses about it, and she said, "oh". Finally, when she would not use her hand to eat, I told another nurse, she took a look at it and said they had better call the doctor at the hospital. I then took her to the hospital where they set the wrist and admitted her, because she also had a urinary infection and was dehydrated. (See attached Public Health report.)

During this time, I had taken Mom to the dentist to get her top denture replaced. She hated the procedures at the dentist because the molding plastic in her mouth scarred her. Finally, in December she got the upper teeth. She looked so much better, and liked how she looked in the mirror again.

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In mid-January they lost her lower dentures, ~~THEY DIDN'T KNOW WHAT HAPPENED TO THEM!~~. She did fair with just the upper teeth, she could still chew somewhat.

Now (as of February 1, 1989) they have lost the BRAND NEW UPPER DENTURE. She is now completely without any teeth!!!! And, we have to start the whole procedure over again, which she hates, for both the bottom and top.

Also, during this time, her hearing aid (which she cannot take out of her ear by herself because the fit is really correct and tight) was missing. They said, "well it must have fallen out at night in the sheets". They found it about a week later, completely non-functional. They think it must have gone through the wash!! I have since had this repaired and it is back in her ear - for God knows how long - before it is missing completely or broken again.

Also, I am again afraid for her safety. Mom a lot of times will hit anyone who she thinks will hurt her, when they do things to her instead of having respect for her and talking to her and asking her to do this or that, or if they can do this or that for or to her. The aid, Larry, off and on had told me belligerently that "your Mother kicked me again". Finally, the one night I was walking past him and he again belligerently said she kicked him. I did not acknowledge his comment, and walked almost past him. He then said in a very nasty tone "Did you hear what I said!" I turned and told him that I didn't like his tone, and what did he want me to do about it. He then menacingly said "Nothing, I'll do something about it." I then ask him what. He stammered around and finally said "I'll call the police". I called the Administrator and told him what had happened and that I felt this was a threat toward my Mother, and that I had heard this aid verbally abuse and mock the patients on the floor. I just recently heard him complain about a new resident - the resident didn't like the chili they served for the evening meal. He told the other aid, just leave it there and the resident will have to eat it if there is nothing else, and it looked like they would have trouble here (in other words have to do something for this new resident because the resident hadn't learned yet not to make waves!) The administrator said "No, that wasn't a threat" and he would talk to him, as they had had a problem with him before. I have heard nothing since then. The aid is still there.

-Just recently, I came and found Mom's knee all swollen. I asked the aid about it, and she said "I wondered why she wouldn't get up from the chair and she was crying". No one had bothered to check. They are underpaid, shorthanded, overworked and most (not all) don't give a damn, that's why. Doctor ordered medicine on

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1/13/89. I came in on 1/20/89 and her knee was still swollen. I asked the nurse if we could give her the medicine because the knee was still swollen. The nurse took the bottle out of the med cart, and we both at the same moment saw that the bottle was 99% full. Illinois Department of Regulations is looking into this matter.

Also, supposedly these homes get QUIP money for special programs for their Alzheimer patients. There are none that I know of for Mom! The second floor of this home doesn't have much of anything for the patients.

And on, and on, and on it goes. A nursing home (as nursing homes are today) is no place for any human being, let alone a person with Alzheimer's.

What more does my Mother have to endure just because she was unlucky enough to get Alzheimers and not have a lot of money????

I am requesting, from Public Aid, that they pay for her 24 hour care AT HOME.

Any help you can give me to get her home would be greatly appreciated.

Judy Worn

Judy Worn
6209 S. Spaulding
Chicago, IL 60629

216-2461 (Work)
471-1269 (Home)



March 21, 1989

Sen. Paul J. Simon
230 S. Dearborn St.
Suite 3892
Chicago, IL 60604

Dear Sen. Simon:

At your March 13 hearings on the need for effective, public supported long-term care you stated that statements supporting this position could be submitted to you for inclusion with the official testimonies.

The Chicago Gray Panthers attended the hearing. We want our statement to be included.

We believe that such long-term care, given in a variety of ways appropriate to the individual's circumstances, and federally funded, is absolutely necessary, but that it be one significant provision of a NATIONAL HEALTH SYSTEM, which would end the present fragmented, partial, and inequitable health distribution from which a large number of our population suffers.

Thank you for our invitation to include this statement.

Sincerely,

Agnes J. Hansen
Agnes J. Hansen
Convener

PREPARED STATEMENT OF THE ALZHEIMER'S ASSOCIATION

ALZHEIMER'S ASSOCIATION LONG TERM CARE PRINCIPLES FOR FEDERAL LEGISLATION

The Alzheimer's Association, representing over 4 million people with Alzheimer's Disease and related disorders and their families and caregivers, is particularly sensitive to the unmet need for home, community-based and facility-based long term care and services. Long term care affects all age groups and services should be provided to, and paid for, by all Americans. The Association believes there is immediate need for a federal, universal and comprehensive long term care social insurance program that is "dementia friendly." The Association supports the following principles for long term care reform:

BENEFITS/ELIGIBILITY

1. Eligibility for long term care services in all settings should be extended to all individuals who need them, regardless of age, income, marital status or informal social supports.
2. Eligibility should go beyond traditional measures of disability to include functional, cognitive or behavioral limitations, including the need for supervision because of risk to safety or health or the need for verbal reminding or physical cuing. Eligibility determination should be flexible enough to reflect individual situations.
3. Both public and private long term care insurance programs must cover care provided to Alzheimer's Disease and related disorders patients.
4. Benefits should provide needed services at all levels of care, ranging from a comprehensive system of home and community-based services to facility based services. Services should be provided in such a way as to maintain and enhance personal independence in the community and in the setting preferred by the beneficiary and family.
5. The long term care benefit package should allow maximum flexibility in meeting individual client needs. Direct and indirect services and supplies including items needed to maintain patients at home such as consumable care supplies, should be covered benefits.
6. The program should consider the needs of both beneficiaries and caregivers as appropriate recipients of services. Patient socialization, caregiver respite and other support services should be covered in all settings.
7. Facility based care should be covered in its entirety, regardless of the length of stay.
8. The program should assist families and other informal caregivers. Families should be a primary part of care coordination and beneficiary and family care preferences must be considered in planning and coordinating care. Care coordination should also support, rather than supplant, client and family decision making. There should be no disincentives to family participation; nor should providing informal care be a prerequisite for formal care.

9. Adequate education and training for long term care providers is an essential component of care; provider training must incorporate instruction specific to the care needs of dementia patients. The long term care program should also offer education and training for informal caregivers.
10. The program should ensure high quality care. In order to help ensure quality and access, programs should be monitored, and providers should be carefully screened, well trained and adequately supported and compensated. Efforts to enhance meaningful quality assurance should take special account of the situations faced by patients with Alzheimer's disease or a related disorder.
11. The program should ensure access to services for all. No patient or family should be denied access to information or services because they refuse to relinquish control of care planning to an agency, professional or team.
12. Research should be conducted on more accurate measures of disability and on the adequacy of services to meet patient and family long term care needs.
13. Special provisions should be made to assure that those who lose cognitive function maintain rights to make appropriate care and treatment decisions to the extent of their ability and that their legally designated agents maintain rights to make decisions for them to the extent necessary due to their cognitive impairments.

FINANCING

14. The long term care program should be based on traditional social insurance principles and spread the financial risk as broadly as possible. Its structure should not require the impoverishment of individuals or families.
15. Basic long term care coverage should be made available to all eligible individuals. The program should provide benefits to members of all generations and these costs should be shared equitably across generations. Private insurance may offer supplemental coverage, and standards should be set to protect consumers.
16. Means-tested programs such as Medicaid should not serve as the basis of the federal long term care program; coverage and financing should be uniform throughout the nation and should not stigmatize those in need.
17. The new public program should be supported through sources of financing that are as progressive as possible.
18. Protection from out-of-pocket costs for low and moderate income persons should be provided.
19. Cost containment should be built into the program. The public costs of the program should be minimized while meeting consumer's needs.

Senator SIMON. Our first panel will be made up of Mrs. Mary Paul, Mr. Jim Spiro and Ms. Helen Anderson. If the three of you can please come here. I have seen two of the three of you already.

And let me just comment. Two of these three witnesses will be talking about cases that do not involve seniors. We tend to think of long-term care as only involving senior citizens. There are others who have problems who are not senior citizens. Let me call first on Mary Paul, whose own mother is here. I met her as I traveled through the audience. And if you can pull that microphone fairly close to you. I am not sure which micro-phone is the hot one. One of them is for our recorder.

STATEMENTS OF MARY PAUL, JIM SPIRO, AND HELEN ANDERSON, PRIMARY CARE GIVERS

Mrs. PAUL. As the parent of a 9 1/2-year old boy who is ventilator dependent, and who has from birth, required constant care due to his severe physical handicap, I consider myself uniquely situated and unusually qualified to comment upon the issue of long-term care. I am deeply concerned about the services which are and, all too often, are not available to those of us seeking to make our lives a little more normal, a lot less stressful. Among my concerns are financial services, to insure my child the quality of care he must have in order to live, community and social support services, and the long term implications of caring for and providing a quality life for a ventilator dependent child.

There is so very much that must be done in order to insure a quality life for technology dependent individuals and their families. There are over 450 persons in Illinois alone who are unable to breathe without the aid of mechanical ventilation, and I am certain that the number of people needing such long-term care is growing and will continue to grow. The shame is that these individuals have been created by advanced medical technology and then largely abandoned by their creators to communities unprepared, unable and even unwilling to provide sustained backup or concrete help and support.

My son's need for constant monitoring and the administration of various medical procedures is more than can be met by one or two members of a family. Yet, private insurance cannot be relied upon to provide payment for the tremendous expenses involved in long-term care of technology dependent individuals. At the time of his hospitalization, my son was covered by three insurance policies, by reason of my husband's previous and current employment. Since then, his primary insurer has paid out a life time major medical maximum of \$250,000 and no longer can accept claims, while Cook County, which insures my son through a group policy has rewritten its policy with our now primary insurer, effective March 1st. The new policy limits payments for private duty nursing to \$1,000 per month, an absolutely unrealistic figure if you consider our nursing bills run approximately \$16,000 per month, and my husband and I assume over one-third of the shifts ourselves in an effort to contain costs and afford ourselves a modicum of family life and privacy. We do have a tertiary insurer to fall back on for the time being, but I

constantly wonder and worry what will happen if they too are directed by the employer to change the terms of their policy.

To say that living with a technology dependent child or adult and being the primary caretaker of a person with long term health care needs is stressful is a woeful understatement. Our son must constantly be monitored, 24 hours a day, every day. His medical and personal needs are unceasing. Yet he is a normal nine year old boy. He wants to play; he needs and wants a mom and a dad, not just primary caretakers. Balancing the vital medical and personal needs care he requires against his needs as a nine year old, as well as our needs, is a most difficult, stressful and exhausting endeavor.

Although he is totally dependent on others and on mechanical means for every conceivable physical need, my son is an inspiration. He has never given into self-pity or even complained. With an IQ of 162 he has the potential, should he live, to find a cure for his own disease. On the very rare occasions when I imagine a future for him, I think of Stephen Hawking, the present occupant of Isaac Newton's chair as Lucasian Professor of Mathematics at Cambridge University. Professor Hawking is only in his mid-40's but has had ALS, a motor neuron disease, as is my son's, for many years and is severely physically limited. He has been ventilator dependent for some years, and yet he is regarded as undoubtedly the most brilliant theoretical physicist since Einstein. How very wonderful it would be if my son, and others like him who are technology dependent and require long-term care, could look forward to the kind of productive, meaningful and contributory life that Stephen Hawking has. How very wonderful, how very humane it would be if these individuals were guaranteed the care they need in order to fulfill their potentials free of the worry and frustration we have experienced in our constant and never ending effort to assure quality care for our son.

Senator SIMON. Thank you very, very much, Mrs. Paul. So that we understand, when you talk about ventilator dependent what does that mean?

Mrs. PAUL. Due to the fact that my son's lungs do not function very well at all he is not able to breathe on a sustained basis on his own. He has had a tracheostomy performed and he is attached to a ventilator, sometimes it is better known as a respirator, most of the day and all night for breathing purposes. The machine actually delivers breaths to him.

Senator SIMON. And you are fortunate to have some insurance coverage.

Mrs. PAUL. Yes.

Senator SIMON. We have 38 million Americans who have no insurance coverage whatsoever. What would happen if, to your family, if you had no insurance coverage?

Mrs. PAUL. I would understand that in effect we would go on partial aid from the Division of Services for Crippled Children, which would provide us with a minimum amount of nursing services. Also, I believe, they would pay for our supply bills. I mean the ventilator requires a good deal of supplies, between say \$500 and \$800 a month worth of supplies to keep it functioning. After we exhausted the DSCC Services and our own resources there is nothing left.

Senator SIMON. In your case, you have had the good fortune of having three insurance policies.

Mrs. PAUL. Right. But as I pointed out, one has paid out its major medical lifetime maximum and no longer accepts claims. The second one is now limiting us to \$1,000 per month for nursing care when our bills run approximately \$16,000, and that covers only two-thirds of a month. We pay one-third of it ourselves. And that was recently changed. So, in other words, insurance can be pulled out from under you.

Senator SIMON. Right. So the need for long-term care is there.

Mrs. PAUL. Is overwhelming.

Senator SIMON. Is overwhelming. Thank you very much.

[The prepared statement of Mrs. Paul follows:]

PREPARED STATEMENT OF MARY M. PAUL

When our son was born there was no indication whatsoever of the multitude of problems which were to lie ahead. He appeared to be a perfectly healthy, thoroughly normal baby. However, when he was only ten months old he was diagnosed as having Werdnig-Hoffman Disease or Infantile Progressive Spinal Muscular Atrophy, and we were told he wouldn't live past his second birthday. Fortunately he did, but at the cost of repeated hospitalizations for severe pneumonia, usually accompanied by a partially collapsed left lung. Although we had been asked if we wanted our son to be kept alive by heroic means should the need arise, which was virtually inevitable, we chose to no-code him--an incredibly difficult decision, but one that was rooted in the fear of a future dependent on mechanical ventilation and uncertain care.

Not too long after his seventh birthday he developed a large mucous plug which blocked his airway and led to full respiratory arrest. I will never forget the terror and despair I felt that night as I frantically and ineptly attempted to breathe life back into him in my own living room. Somehow I succeeded, but he was intubated on an emergency basis before we were consulted. Although gravely ill and now even unable to talk because of the tube in his airway, he fought for life and regained his spirit almost at once. Unfortunately, he failed extubation, a tracheostomy was performed, and he was placed on a ventilator--for life.

It is not easy having a child or a loved one dependent on a machine for something that, until the advent of very recent technological developments, is the most biologically natural function--breathing. It's not just the terrible pain we feel at the turn of events that made ventilator assisted breathing necessary. It's also the unbelievable disruption in our lives as we knew and lived them. Change isn't the easiest of life's events to cope with, even when it is something relatively inconsequential. But to undergo the kinds of changes required when your child is placed on a ventilator is virtually devastating. Then it becomes apparent that what remains of your life is in the hands of strangers, some of whom are caring and compassionate, others of whom are merely doing their jobs, with widely varying degrees of skill. You, as a parent or an individual or a family, are seldom consulted, much less encouraged to take an active roll in managing your own case. Yet he is my child; I am ultimately responsible for him; I know him better than anyone else ever could; I am willing to give up my life for him.

My husband and I had cared for our son by ourselves with absolutely no outside assistance, except for family and friends, for well over seven years before he became ventilator dependent. We were a well functioning family and had made all the adjustments we deemed necessary to our "special circumstances." Now we had a whole new "special circumstance" to adjust to and were faced with caveats that we did not always feel were in the best interests of our son and our family. I wanted to resume, as much as possible, what was for us a normal life; I wanted to be consulted, involved, informed; I wanted someone to listen to my anger, frustration and

pain and help me to overcome them and get on with my new life. Instead I got a formulated discharge manual and a standard care plan, neither of which allowed for individual differences or abilities or bore any real resemblance to the life style I was trying to maintain, albeit within the framework of significantly altered circumstances.

As soon as we were able to get my son home, all the carefully crafted but rigid plans began to fall apart. Although my son's discharge was contingent, in part, upon notification of all the utility companies of our absolute need for power, phone service and heat, we hadn't been home for more than two weeks before we had a power failure. When I telephoned the power company, I was told there was nothing they could, or would, do, and if I needed power to run my son's ventilator, I would have to take him to a doctor's office or a hospital, a rather impractical solution in inclement weather or if the outage were to be prolonged. Each of the five times in the last two years that we have lost power, I have telephoned Commonwealth Edison and received variations on the same reply. I have, luckily, not had to test the phone or gas company, but I certainly am not sanguine as to their probable responses.

The overriding concern on which our discharge was predicated was, of course, financial. Who was going to pay the enormous cost of keeping my son alive? Fortunately, he was, at the time of his hospitalization, covered by three insurance policies by reason of my husband's previous and current employment. Since then his primary insurer has paid out a life-time major medical maximum of \$250,000 and no longer can accept claims. His secondary, and now primary insurer was less than forthcoming in their cooperation when they were presented with our unpaid nursing and supply bills (as well as a host of lesser expenses). They actually stonewalled on making any payments for over nine months until they ran out of excuses and our unpaid nursing bills alone amounted to over \$150,000. Then they most reluctantly paid out the \$100,000 that was our son's yearly major medical maximum. We are now dependent upon his tertiary insurer to pay the balance, and they have just begun to study the case.

In the meantime, the County of Cook, which insures my son through a group policy, has rewritten its policy with our now primary insurer, effective March 1st. The new policy limits payments for private duty nursing to \$1,000 per month, an absolutely unrealistic figure if you consider our nursing bills run approximately \$16,000 per month, and my husband and I assume over one-third of the shifts ourselves in an effort to contain costs and afford ourselves a modicum of family life and privacy. Although we have strongly protested this change in coverage, and perhaps due to a fit of paranoia, believe it to be directed against us personally, we have not heard from the County on our request for a waiver from this provision. We do have our tertiary insurer to fall back on

for the time being, but I constantly wonder and worry what will happen if they too are directed by the employer to change the terms of their policy.

To say that living with a technology dependent child or adult and being the primary caretaker of a person with long-term health care needs is stressful is a woeful understatement. Our son must constantly be monitored--24 hours a day, every day. His medical and personal needs are unceasing. He must be suctioned, fed, dressed, bathed, toileted, educated and so on. He needs someone to scratch for him if he itches, wipe away his tears if he cries or move his legs if they become cramped. Yet, he is a normal nine-year-old boy. He wants to play; he needs and wants a mom and a dad, not just primary caretakers. Balancing the vital medical and personal-needs care he requires against his needs as a nine-year-old, as well as our needs--as mundane as cooking dinner or as necessary as sleep--is a most difficult, stressful and exhausting endeavor. Still, every day additional difficulties present themselves--the insurance is slow to pay or expires; a piece of equipment malfunctions; the nurse is unable to come and there's no one to back her up so I simply cancel anything I may have planned, no matter how important, and so on. And there is no one you can call or turn to or seek help from unless you are as blessed as we are to have the neighbors we do. These people have provided the only real, sustained backup and concrete help that we have received in the last two years. Although we should move as our house is most unsuitable for a handicapped child, we can't. We are afraid to remove ourselves from the one source of constantly available and unquestioning physical support that is open to us.

There is so very much that must be done in order to insure a quality life for technology dependent individuals and their families. There are over 450 persons in Illinois alone who are unable to breathe without the aid of mechanical ventilation, and I am certain that the number of people needing such long-term care is growing and will continue to grow. The shame is that these individuals have been created by advanced medical technology and then largely abandoned by their creators. There isn't even a charitable and/or service agency that is concerned about my son's inability to breathe. The need for constant monitoring and the administration of various medical procedures is more than can be met by one or two members of a family. Yet private insurance cannot, as I have indicated, be relied upon to provide payment for the tremendous expenses involved in long-term care of technology dependent individuals. We are comfortable as far as our economic situation is concerned, but funding is a constant source of deep concern for us as our resources, financial as well as emotional, are by no means unlimited. And we are at the mercy of our employers who, as Cook County has just done, may decide they don't want to fund the care my son requires, despite the fact that, expensive though it most certainly is, home care is a great deal less costly than in-hospital care.

I would like to say that, despite the severity of his handicap and his dependence on a ventilator, my son is one of the greatest kids I've ever met. He is totally dependent on others and on mechanical means for every conceivable physical need. Yet he has never once given in to self-pity or even complained about anything more serious than having his fingernails cut. He is an inspiration, and with an IQ of 162 he has the potential, should he live, to find a cure for his own disease. On the very rare occasions when I imagine a future for him, I think of Stephen Hawking, the present occupant of Issac Newton's chair as Lucasian Professor of Mathematics at Cambridge University. Professor Hawking is only in his mid-forties but had had ALS, a motor neuron disease as is my son's, for many years and is severely physically limited. He has been ventilator dependent for some years, and yet he is regarded as undoubtedly the most brilliant theoretical physicist since Einstein. How very wonderful it would be if my son and others like him who are technology dependent and require long-term care could look forward to the kind of productive, meaningful and contributory life that Stephen Hawking has. How very wonderful, how very humane it would be if these individuals were guaranteed the care they need in order to fulfill their potentials.

I am so very thankful that our original decision to no-code our son was taken out of our hands. I only hope and pray and appeal to you never to let him experience the worry and frustration we have in our constant and neverending effort to assure quality care for him.

Mary M. Paul
4948 N. Mulligan
Chicago, IL 60630
(312) 775-7379

Mary M. Paul
4948 North Mulligan
Chicago, Illinois 60630
(312) 775-7379

Biographical Information

Born Mary Frances McCue, September 27, 1942, Chicago, Illinois. Graduated York Community High School, Elmhurst, Illinois, 1960. Bachelor of Arts (with Honors) in history from Northern Illinois University, 1964. Master of Arts also in history (concentration in East Asian History) from N.I.U., 1970. Employed eleven years, 1966 through 1976, with Mitsubishi International Corporation, Chicago Branch, as Assistant Traffic Manager, Metals Division. Self-employed ten years as tax preparer/personal accountant. Married, 1970, to Alfred J. Paul, presently employed as an Associate Judge in the Circuit Court of Cook County. One child, Daniel J., born July 21, 1979, who is severely physically handicapped (Werdnig-Hoffman Disease) and ventilator dependent since respiratory arrest in November 1986. Currently attending Wright College pursuing a major in accountancy and occupied full time as primary care-giver to son. Served as a panel member of LaRabida Conference on ventilator assisted children, 1987, member of Ventilator Assisted Individuals of Illinois Study Steering Committee, 1987-88, and participant in DSCC video projects for hospital discharge and home care planning for technology-assisted children, 1987-88.

Theme of Speech

As the parent of a 9½-year-old son who is technology dependent and who has almost from birth required long-term care due to his severe physical handicap, I consider myself uniquely situated to comment upon the services which are and, all too often, are not available to those of us seeking to make our lives a little more "normal", a lot less stressful. Among my concerns are financial services (to insure my child the quality of care he must have in order to live), community or social support services, the discharge and follow-up processes and the long-term implications of caring for and providing a quality life for a ventilator dependent child. I feel that ventilator dependent individuals have been created by advanced medical technology and then largely abandoned by their creators to a society unable and/or unwilling to deal with this growing population. (It is of interest to note that as of the end of January 1988, there were 453 individuals in Illinois who were long-term ventilator assisted.)

Mr. SPIRO. Good morning, Senator Simon. I want to thank you for the opportunity to be here today and to tell something about my experiences as a caregiver for my wife, who had Alzheimer's disease for 13 years. In doing so, I hope that I will be able to shed some further light on the problems and the needs that effect millions of caregivers throughout this country.

The very last 8 years of my wife's life she required constant care, and so I retired from active life in order to take care of her needs which increased almost on a daily basis because with Alzheimer's disease you are faced not only with deteriorating physical functions, but mental functions as well. And it is a devastating combination.

It was also a terribly emotional and stressful experience to see a brilliant, bright, active, socially active, loving woman turn into a child, a baby, requiring that everything be done. In Alzheimer's disease the individual fades into the mist bit by bit, physically and mentally until they are completely gone.

I think anyone who just thinks about it from a common sense viewpoint can understand that when there is long term illness, family and friends over a period of time fade away, and the caregiver leads a somewhat lonely existence with mounting problems. Those problems are medical; they are mental; they are financial. The caregiver is filled with all kinds of concerns. Feelings of guilt, concern, bewilderment, and most of all, fear. Fear of what will happen to their loved one if they become ill or if they should die.

Let me give substance to that fear by saying, that in my case during the last three years of my wife's life, I was required to be hospitalized on two occasions. The first time I looked for someone to take care of my wife, remember she could not be left alone, and I found that I would have to pay between \$1,000 and \$1,500 a week for someone to take care of her 24 hours a day, 7 days and nights a week. That was for unskilled help, by the way. There was no other realistic help available.

I was fortunate in that a woman who, herself, was dealing with many personal problems, learned of my plight and volunteered her services. I was in the hospital for 3 weeks, when I came back, I found my wife was well taken care of. But the next year I had a heart attack and required hospitalization again. It took me a week before I could find someone, it turned out to be the same woman, who would be able to take care of my wife. That woman stayed with my wife over 2 1/2 weeks while I was in the hospital, and also stayed with my wife and myself for another week or so until I was able to resume care of my wife.

Now, that kind of situation is not unusual at all because the fact is that those who are well off financially can afford for a fairly long period of time to buy all of the assistance that they may need to take care of their loved ones. If they happen to be in financial distress, some help is available to them, though it is not quite as adequate as it might be. But for the vast majority of caregivers who are in that middle group, there was virtually no help available at all.

The thing is that this problem is growing. There are millions of caregivers out there who desperately need help. The problem is if it

is treated lightly or ignored it is not going to go away. It is only going to increase. So now is the time to do something about it.

I am going to say that here I am at the age of 69, trying to start a new career in order to be able to meet the obligations that were incurred during the past years. I am spending some of my time, however, in working with both the Chicago Area Chapter of the Alzheimer's Association, and the National Alzheimer's Association because I know it is important that people who are in the position that I was in receive real help. And so I, and others like myself, turn to you and your colleagues in Congress, saying we are ready to work with you in developing a genuine solution to this important problem in our country.

Senator SIMON. I thank you very, very much. And I thank you for taking the time to be here and for standing up for people in your situation. You mentioned your wife's illness. She was how old when she got Alzheimer's, when you discovered it?

Mr. SPIRO. Well, it is hard to pinpoint the exact onset of Alzheimer's. But she was approximately 54 years old.

Senator SIMON. And I mention that because what we have to do is obvious, and Mrs. Paul's case is another example. When we deal with long-term care, we can't just deal with those over the age of 65. We are going to have to deal with a broader spectrum of the population.

Mr. SPIRO. It covers the full age spectrum of the population. No question about it.

Senator SIMON. And you mentioned that you are launching a second career in part to pay past bills that you have accumulated because of your wife's illness, at the age of 69 you are doing that?

Mr. SPIRO. It is an economic catastrophe.

Senator SIMON. One family I have talked with, and it happens to be an Alzheimer's case also, have accumulated a total of \$910,000 in hospital and medical bills. Now, how can any of us take care of that? Somehow, all of us, as a society, ought to assume that burden. You shouldn't. I am pleased that you are willing and able at the age 69 to launch a second career, but you shouldn't have to feel compelled to do that. Somehow all of us ought to be able to share that burden. But I thank you very, very much for being here, Mr. Spiro.

[The prepared statement of Mr. Spiro follows:]

PREPARED STATEMENT OF JAMES M. SPIRO

Good morning Senator Simon and members of the Committee. I appreciate the opportunity to appear before you today.

My purpose in testifying is to present some personal experiences in dealing with the problems and difficulties encountered by caregivers to those with illnesses requiring long term care. In doing so, I hope you will better understand the scope of the problem and the need for prompt, effective government action in providing practical assistance to both those who are ill and their caregivers.

The daily life of the caregiver is beset with a whole range of human emotions. There is anger, guilt, despair, remorse, bewilderment, sadness and fear. Family and friends, for many reasons, fade away. The caregiver becomes isolated. Each day brings new problems. Fatigue grows. Economic and legal problems proliferate. As the situation worsens the caregiver worries that he or she may collapse and his or her loved one will be left helplessly alone.

My own experience illustrates the problems. For more than thirteen years my wife, Lee, suffered with Alzheimer's Disease. During that time, she was transformed from a brilliant, vivacious, energetic, loving wife to a person who could not speak, feed herself, bathe, dress or perform any of the basic functions of life. She physically and mentally faded deeper and deeper into the fog and mist generated by Alzheimer's Disease until she was completely gone.

During the last eight years of her life she needed constant assistance. My busy working life during which I had been a practicing lawyer, Army General, college teacher and corporate and association executive came to an abrupt end. I spend 24 hours a day, seven days and nights a week personally attending to her every need. I became nurse, cook, housekeeper, laundress, shopper and companion, handling anything and everything.

There was no respite as the demands on my energy and ability increased. I was my wife's sole caretaker. Other help generally was not available because one had to be financially well off or have become financially destitute. Those of us who are neither face great difficulties.

For example, two years before my wife died, I became ill and required hospitalization. When I looked for someone reliable to take care of my wife full time until the doctors completed their treatment of me, (she could not be left alone), I discovered the minimum cost for unskilled help was \$1,000 to \$1,500 per week. That was beyond my financial ability and the ability of most in that situation. Unusual expenses involved in long term care quickly deplete financial resources.

Fortunately, a woman who herself was dealing with serious problems in her own life learned of my dilemma and volunteered her services. She lived with, and took care of my wife until I was discharged from the hospital three weeks later. I "lucked out."

Desperation set in again when one year later I had a heart attack and needed immediate hospitalization. I searched for a week to find someone to take care of my wife in my absence. A miracle occurred when the same woman who helped me before once again volunteered her services. This time I was in the hospital for two and one-half weeks.

Circumstances like these are not uncommon. Caregivers wear out and become ill. They need respite from the burdens they carry 24 hours every day. If they become ill, who will take care of their loved ones? Unless there are family and friends who can fill the void or a miracle occurs, as in my case, the ill person cannot be left at home. With insufficient funds available for temporary home or institutional care, the patient must be taken care of at taxpayers expense. If that is not possible, the caregiver goes without needed medical care. Then surely the patient at some time will become an obligation of the taxpayer.

Babies with time become stronger and capable of taking care of more and more of their needs. But victims of Alzheimer's Disease and others like them require increased care as they regress to a completely helpless baby-like state. The financial, physical and mental demands on the caregivers increase to the breaking point. These millions of caregivers need help beyond their own resources. Society, and government must deal with the problems now because it will not vanish by being ignored or treated lightly. The situation for many grows desperate. I know, for I have been there and know others who are there now.

Although my wife died two years ago, I am just now beginning to recuperate from those eight demanding years. At the age of 69 I am trying to develop a new career and meet financial obligations incurred in the past.

Simultaneously I do volunteer work with the Alzheimer's Association in various capacities and attend support group meetings to try and aid those who still need help. They are legion.

I, and others like me, ask that you and your colleagues in Congress help by developing and enacting effective long term care legislation which is to desperately needed.

WITNESS BIOGRAPHY

JAMES M. SPIRO
5916 West Diversey Ave.
Chicago, IL 60639
(312) 637-1941

Retired lawyer, U.S. Army General, businessman, college teacher and association executive.

PRESENT POSITION:

Board Member and Advocacy Chairman, Chicago Area Chapter, Alzheimer's Association.

Member, Public Policy Committee, Alzheimer's Association

PRIOR POSITIONS INCLUDE:

-Private law practice

Teacher at Roosevelt University and Chicago City Junior Colleges

Officer in Spiro, Kane & Fee, Inc.; Spiro Brothers Corporations; and National Strategy Information Center, Inc.

Director, Executive Services, Director of Activities, etc., American Bar Association

Army combat infantryman, Italy, W.W.II.

Judge Advocate general's Corps, Korean War

Final position, Chief Judge, Army Judiciary (Mob Des)

Native of Chicago. Born January 1, 1920

Attended:

University of Chicago, A.B.

De Paul University, J.D.

Northwestern University

Army War College

National War College

Senator SIMON. Our final witness in this panel is Helen Anderson, who has a somewhat different kind of a story.

Ms. ANDERSON. Thank you, Senator Simon. Millions of American family members today continue a long tradition as caregivers for elderly relatives. I am one of those caregivers, a widow, with no children or extended family for much needed support. So I am really alone.

My sister, who needs my care giving, is 84 years old, single, and the victim of chronic illness and increasing disabilities which prevent her performing the daily functions of living a normal lifestyle or managing on her own, and returning some element of independence which she desires. For the past month she has been hospitalized. Medical opinion on her deteriorating condition presents a very bleak outlook.

A nursing home has been suggested to me many times, but I have determined to do everything possible to care for her in her home, and with daily expensive help, temporary help, and the availability of affordable help, and even a doctor who will make house calls are only two of the many problems I have, along with concerns of my personal health. True, there are programs out there, but there are also restrictive qualifications for eligibility.

My sister does not have Medicaid insurance, unfortunately. Like many single women, she has saved and budgeted for her retirement years, and these funds that she has are rapidly dwindling, \$10,000 was expended this past year in help and medical care and other needs that she has had. With these funds I have endeavored to purchase long-term care insurance, but find the policies prohibitively expensive and restrictive for certain types of care and illness.

Presently, I am concerned that the only options I have now for my sister's care are around the clock, live-in, semi-skill care at home, or transferred to a nursing home. And the later, raises many emotional problems. It is very difficult to make any decisions contrary to the wishes of a sick person. Medical treatment which would involve surgery, and the doctors for a boning opinion of her future outlook is not good.

I am grateful for the information my membership activities in the Chicago Department on Aging and Disability, and the Older Women's League offer in researching for some answers. I quote Josh Weiner, Senior Fellow of the Brookings Institute, "It would be greatly preferable to recognize that long-term care is a normal, insurable risk for the elderly, which should be covered under a general, social insurance program like Medicare, and not through a welfare program like Medicaid."

I have also noticed that President George Bush, in November before the election, made a statement, "I have proposed a program to help Americans plan for long-term care, including changing the tax code to provide incentives for purchase of long-term care insurance and allowing conversion of other savings to pay for long-term care." Also in his statement he refers to the certification of all nursing homes, focusing directly on residents, their health, and quality of life. It is really a problem to find a certified nursing home.

In conclusion, I join all caregivers who are experiencing the worries, frustrations and demands of care giving daily. Working together, I believe, it is possible to motivate relevant legislation for affordable long-term care services in the home and community for those who can use it, and in certified nursing homes. And I want to thank you for inviting me to speak on this. I know that this is an usual case but there are many thousands that are in the same boat, and I don't know what my next step is.

Thank you.

Senator SIMON. I thank you. And when you say in conclusion you don't know what your next step is, let me tell you there are a lot of people, I don't know if these people out here represent that, but there are a lot of Americans out there who have that same fear: And you mentioned the emotional problem of taking your sister to a nursing home. That is a tough enough thing. We shouldn't compound it with financial problems on top of that. My mother, who is 82, fell down and after her hospital stay they recommended a nursing home because a nursing home could give her therapy. And I remember taking my mother to the nursing home, or being with her right after she was taken there, and then saying good-bye to her. And she, fortunately, was there just about three weeks. But I know, even though my mother has never admitted that she believed this, but she was crying when I left her and I am just sure my mother thought I am being left in this nursing home. There is that problem in and of itself, and we compound it with financial problems.

You mentioned one other thing that is not part of the purpose of this hearing, but I think is important also. You mentioned you need a doctor who will make house calls.

Ms. ANDERSON. I had a difficult time until I contacted the Social Service Department or the Social Service Advocate from the Department on Aging. I asked if she knew of someone on the staff of this certain hospital, and I was finally able to get the Social Service Superintendent, and finally I accepted the doctor that was sent out. But the doctor that was sent out was not on assignment, and the call was very brief, \$175, and \$78 worth of medication and all types of tests that had to be made which I finally refused because it was difficult to get her to the hospital. But I finally managed that on my own.

So I am now going through a series of, I don't know whether they are necessary or not, but I feel that many people are going through this who are under stress, where they don't have an advocate for opinions in the hospitals too. So all you can do is be alert and try to figure it all out, and as far as the nursing home this is the first time I have ever mentioned a nursing home as an alternative. And believe me, it was just heartbreaking, just as you said.

Senator SIMON. You mentioned that the doctor recommended some tests and you are not—

Ms. ANDERSON. Yes. Then I would have to transport her back and forth and she couldn't even get up to be in a wheel-chair. And so finally I just said that that cannot be, and we will just have to arrange through an emergency situation to get her into the hospital, where she is now. But as I said before, I don't know what the

next step is going to be, and I must make plans. So I do thank you for this opportunity.

Senator SIMON. Well, I thank you. Let me just add. There are all kinds of people who not only don't take the tests that some people say they should take, we have now about 100 million, believe it or not, prescriptions that are unfilled each year because people just can't afford the prescriptions. Now, in some cases, frankly, I think they are maybe better off if they don't fill the prescriptions. (Laughter)

But you know, you shouldn't have to be making a decision about something that you may need for good health because of finances in the richest nation in the world.

Ms. ANDERSON. Insurance would be so helpful.

Senator SIMON. And your problem, Ms. Anderson, is frankly, more typical than the problem that Mrs. Paul and Mr. Spiro face. And the majority of those who need this long-term care are people over the age of 65.

I thank all three of you very, very much. It is not easy and pleasant to get up and talk about your problems. Thank you very, very much. (Applause)

[The prepared statement of Ms. Anderson follows:]

PREPARED STATEMENT OF HELEN F. ANDERSON

Millions of American Family members today continue a long tradition of caring for elderly relatives. Family care-givers provide between 75 and 90% of the personal care, household maintenance, transportation and shopping for older persons no longer able to perform these daily functions. I am one of these care-givers, a widow with no children, or extended family. My sister is 84 years old, single, who suffers chronic illness and disability which prevent her from managing on her own. A nursing home has been suggested, but I have determined that as a last resort, and have been doing everything possible to keep her in her apartment with temporary help. Availability of help, and even a doctor who will make house calls, are only two of the many challenges I face.

Deciding how best to arrange for care is most difficult even when dwindling resources are available to purchase even limited care. Medicare is available for acute care in a hospital where my sister is at present. She does not have supplemental insurance like thousands of today's elderly, who have saved and budgeted to provide for retirement years. Private long term care insurance policies are expensive now, often restricting benefits for certain types of care, only. Medicaid does cover the cost of long-term nursing home care. But if a person does have savings, she literally has to impoverish herself to qualify for care in a nursing home, which means first "spending down" or exhausting assets.

Presently, I am concerned about the only option left open for my sister since around the clock care at home does not seem feasible. I have considered this as a last resort. I am now researching information provided me as an active member of the Chicago Department on Aging and Disability, the American Association of Retired Persons, and the Older Women's League. True, there are programs out there, with long waiting lists and restrictive qualifications for eligibility. I am grateful for the offers to help finding a desirable nursing home, and one affordable.

In conclusion, I join all care-givers who are daily experiencing the worries, frustrations, and demands concerning long term care, and researching the quality of care in a nursing home. Let us work together for necessary reforms!

(continued)

LONG TERM CARE HEARING

MARCH 13, 1989

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From Mrs. Helen F. Anderson

I should like to include the following statements:

From Josh Weiner, Senior Fellow, The Brookings Institution, in testimony he presented at a hearing before the Sub-committee on Health Ways and Means Committee, U. S. House of Representatives, August 4, 1988

"It would be greatly preferable to recognize that long term care is a normal, insurable risk for the elderly, which should be covered under a general social insurance program like Medicare and not through a welfare program like Medicaid."***

Also a reminder of President George Bush's statement issued before the November election:

LONG TERM CARE

"I have proposed a program to help Americans plan for long-term care, including changing the tax code to provide incentives for purchase of long-term care insurance and allowing conversion of other savings to pay for long-term care. For those who cannot afford long-term care, we should change Medicaid requirements that force people to "spend down" their life savings before the spouse is eligible for assistance. We should continue to fund at adequate levels research on disease such as Alzheimer's and strokes.

"I strongly support efforts to improve the quality of care in nursing homes.

"Our administration has recently instituted a new process to certify nursing homes, focusing directly on residents, their health, and quality of life. It reflects a renewed emphasis on the quality of care.

"Another area of concern is discrimination by nursing homes against patients eligible for Medicaid. I support these reforms, and my administration will enforce them."

Again, these statements should be priorities to motivate relevant legislation in the 101st Congress.

Helen F. Anderson



Bio for Mrs. Helen F. Anderson

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Long Term Care Hearing - March 13, 1989

Native Chicagoan

Education: Mundelein College

Engaged in public relations work; retired in 1947; married Elmer F. Anderson; widowed in 1983.

A volunteer since 1947 in national, state, and local organizations.

Held elective office in executive categories in community, service, civic organizations, and religious groups.

Special interest at present: Social Justice, intergenerational activities, all concerns for the elderly.

Presently holds an elective position in the Chicago Department on Aging and Disability, as Community Advisory Group (CAG) representative from the Northwest Area Multipurpose Center; member of Legislative Committee, DAD Advisory Council. Northwest Chapter, American Association of Retired Persons (ARP) Legislation. Board Member - Older Women's League (OWL)

Senator SIMON. Our next panel is composed of Mr. Robert S. Ahrens, Ms. Jan Schakowsky, and Ms. Connie March. And while they are coming up here, Mr. Ahrens is the Commissioner of the Department on Aging and Disability for the City of Chicago, Ms. Schakowsky is Executive Director of the Illinois State Council of Senior Citizens. I notice your President, your boss, is right down here. And Ms. Connie March who is the Vice President of the Geriatric Services of ServantCor from Kankakee. Very happy to have all three of you here.

Bob Ahrens, we will call on you first. Very pleased to have all of you here. Let me just mention for these witnesses and the others, if you have longer statements we are going to have to keep them brief in order to move along rapidly. If you have longer statements we will enter those in the record.

**STATEMENTS OF ROBERT S. AHRENS, JAN SCHAKOWSKY, AND
CONNIE MARCH, A PANEL ON STATE AND LOCAL EFFORTS**

Mr. AHRENS. Well, I want to start by saying good morning and to welcome the Senator and his staff, and all of you out there who I don't know and haven't welcomed somewhere already, to the Department's Central West Regional Center for the Elderly and Disabled. We are delighted to have you all here in a hearing as critical as this is.

I am speaking today for my department, also the Illinois Association of Area Agencies on Aging, the Chicago Advisory Council on Aging, the Chicago Advisory Council on Disability. Time limitations preclude all but a summary, therefore I would like to enter into the record three items: One, the written statement I have developed; two, joint resolution on long-term care by both the Advisory Council on Aging and Disability; and three, the study done by the City of Chicago on long-term care in Chicago planning for the year 2000, a Task Force that I chaired and that our department authored along with the Health Systems Agency.

Senator SIMON. We will enter the first two in the record. Since we are going to print the record that third one looks like a pretty good size. Is there a summary available?

Mr. AHRENS. There is an executive summary.

Senator SIMON. OK. We will enter the executive summary of that in the record.

[The prepared statement of Mr. Ahrens follows:]

PREPARED STATEMENT OF ROBERT J. AHRENS

Good morning, Senator Simon and distinguished members of the panel. I welcome you to our Central West Regional Center, one of five such regional multi-purpose centers for the elderly and persons with disabilities operated by Chicago's Department on Aging and Disability. I applaud you for your concern on long term care, a vital issue for all of us.

I come before you today in a dual capacity, as the representative of the Illinois Association of Area Agencies on Aging and as Commissioner of Chicago's Department on Aging and Disability. The Illinois Association of Area Agencies on Aging is a voluntary grouping of the thirteen not-for profit and public organizations that have been designated by the Illinois Department on Aging to prepare area plans on aging and to develop and maintain local comprehensive and coordinated community networks of supportive and nutritional services for the elderly. The Illinois Association of Area Agencies on Aging has been working with the national Long Term Care '89 campaign to create a long term care delivery system.

Chicago's Department on Aging and Disability is the municipal agency that serves both the older population and persons with disabilities in Chicago by planning, coordinating and delivering services, advocating on behalf of these persons and managing grants to and contracts with community based organizations for supportive and nutritional services. The Department has served, under the Older Americans Act, as the Area Agency on Aging for the City of Chicago since 1974.

I am pleased to be here today so I may emphasize the need to develop a coordinated approach toward ensuring the availability of and access to long term care. Such a coordinated system of institutional, community-based and in-home long term care must include acute hospital care, home health care, nursing home care,

hospice care, affordable and accessible housing for the elderly and disabled, mental health services, congregate dining, in-home services such as chore/housekeeping and home delivered meals, adult day care, education and recreation, employment and job training programs, accessible transportation and adequate retirement income. Clearly, as the number of older persons increases and the average age of the elderly increases there will be additional demands for all of these services. In 1980, 11.3% of the nation's population was 65 years of age or older. As a result of a longer life expectancy and the aging of the "baby boom" generation, by the year 2010, 13.8% of the country will be over the age of 65 and 6.7% of the country will be age 75 or older. Persons 80 years of age and older comprise the fastest growing age group of our population. I think there is increasing recognition of the meaning of these demographics.

Chicago's Department on Aging and Disability and the Chicago Health Systems Agency issued a joint report in 1987 entitled: Long Term Care In Chicago: Planning for the Year 2000. This report was the result of two years of effort in conducting public hearings, community forums and staff research. During these two years, comments were elicited from consumers, health care providers and other experts on the broad spectrum of services that individuals need in order to support functionally independent lifestyles. The primary findings of the report were that fragmentation and insufficient funding were serious problems with the existing system of long term care services. The report recommended more than 100 specific actions leading toward the development of a comprehensive national long term care system. Among these were:

- 1) The federal government should establish a five year program culminating in universal comprehensive long term care for all.
- 2) Medicare premiums, deductibles, and co-insurance for all covered services should be reduced so they create no impediment to access of preventive care and early

intervention.

3) The State of Illinois should establish minimum standards for private long term care insurance policy coverage and marketing practices.

4) City and/or State government should establish a licensure system of all long term care services, which would include a requirement for case assessment and inter-service linkages.

5) City government should establish a case management and inter-service coordination function that is combined with the monitoring and enforcement of licensure standards.

Our Department on Aging and Disability recommends that any long term care legislation should provide for:

- 1) Voluntary enrollment
- 2) Eligibility determined by the inability to perform two or more activities of daily living or the existence of cognitive impairments which require constant supervision, without regard to age and without exclusions for Alzheimer's Disease or AIDS victims
- 3) A broad range of institutional, community-based and in-home services to be covered, including but not limited to day care, respite care, housekeeping and personal care, skilled and intermediate care, home health care, and hospice care
- 4) Rules promulgation within 180 days of enactment
- 5) A distinct and central role for area agencies on aging in the coordination of the long term care system and
- 6) Financing that spreads the cost of the program in an equitable manner to the general population in contrast to the financing arrangement found in the Medicare Catastrophic Coverage Act of 1988.

With these six points as basic guiding principles, I look forward to working with you and other members of Congress to effect passage of a comprehensive long term care law that we can be proud of and that truly serves the needs of the people.

I want to take this opportunity to thank Congress for including language in the Older Americans Act Amendments of 1987, which we supported strongly, to establish a new Title III-D with separate funding for in-home services to frail older persons. Under this new Title, Area Agencies are responsible for developing local community-based long term care services and acting as a facilitator or coordinator for these services for older persons. While this was an encouraging first step to recognize the great needs of homebound and frail older persons, it does not constitute the necessary comprehensive approach to dealing with the situation that a long-term care law would provide. I urge you and your fellow members of Congress to continue and enlarge the financial commitment to this program, which is a vital component in the overall system, while we seek a full solution.

As you are aware, Illinois has established a Community Care Program funded through State General Revenue Funds. The Community Care Program provides community based services to frail older persons and persons with disabilities who are at risk of institutionalization. Ironically, as the State has increased funding for the Community Care Program, State General Revenue Funds for other components of a coordinated approach to addressing the needs of the elderly have been reduced or just not appropriated, notably \$3.2 million previously awarded to Area Agencies on Aging for the maintenance of supportive and nutritional services, \$3 million needed to expand the home delivered meals programs, and \$3 million to implement the Elder Abuse law. Any assistance and support that you might be able to provide in obtaining these crucial State dollars would be appreciated by the aging network.

At this time, I would like to present to you a copy of our study on Long Term Care in Chicago: Planning for the Year 2000, and a copy also of a joint resolution approved in February 1989 by both

the Department's Advisory Council on Aging and the Advisory Council on Disability. The resolution outlines their views on the necessary components for national long-term care legislation. The work of the two advisory councils followed from independent studies by each council's Legislative Committee into the questions and problems facing persons in need of long term care and the provisions contained in major long term care proposals introduced in the 100th Congress including the Kennedy-Simon bill (S 2681), the Pepper-Simon bill (S 1616), the Mitchell bill (S 2305), the Melcher bill (S 2671), the Waxman bill (HR 5320) and the Stark bill (HR 5393).

I hope, along with my friend Jerry Auerbach of southern Illinois, that we may fashion a Medicare Program in three parts, A for acute care and hospitals, B for medicine and doctors and C for long term care at home as well as in institutions.

Thank you again for providing me with this opportunity to express our views on this critical issue as you continue your important task of improving the lives of the people of our great country.



City of Chicago
Eugene Sawyer, Acting Mayor

Department on Aging
and Disability
Robert J. Ahrens
Commissioner

510 North Dearborn Court
Chicago, Illinois 60611
(312) 744-4016 (Voice)
(312) 744-6777 (TDD)

March 15, 1989

The Honorable Paul Simon
Dirksen Senate Office Building
Suite 462
Washington, DC 20515

Dear Senator Simon:

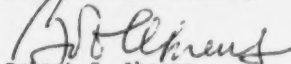
As we discussed at your hearing of March 13 on long-term care, at which I presented you with our full study on Long Term Care in Chicago/Planning for the Year 2000, an Executive Summary is available, although not so labeled.

I am enclosing copies of pages one through eight of the report, an overview, titled Introduction, and of pages 261 through 287, the Conclusions and Recommendations, to serve as that summary.

I thought the hearing came off most successfully, and surely most satisfyingly for you, with your phone call from Abe Stolar.

If we can provide any assistance in getting a good long-term care bill through the Congress, please let us know.

With all best wishes,


Robert J. Ahrens
Commissioner

/lf

Enclosure



Introduction



LONG TERM CARE IN CHICAGO PLANNING FOR THE YEAR 2000

Prepared for the
Long Term Care Task Force
of the
Community Services Subcabinet
of the City of Chicago

by the
Health Systems Agency
and
Department on Aging and Disability



Susan L. Weed
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Released 3/30/87

R. Ahrens

INTRODUCTION

OVERVIEW

Long term care for the elderly is not just nursing homes. It includes all of the services that the elderly may use to support their functionally independent lifestyles. These services may be supplied at home or in an institution, by friends, family or vendor, continuously or episodically, systematically or haphazardly. They range from medical treatment of acute conditions, through custodial institutional care, to community based services that satisfy selected, narrowly defined needs. As a whole, long term care for the elderly is the complete array of services intended to minimize the effects of the functional disabilities that are common to old age.

This study examines a number of long term care services:

- acute hospital care
- primary medical care
- home health care
- nursing home care
- hospice care
- housing for the elderly
- mental health services
- congregate dining
- in-home services
- adult day care
- education and recreation
- employment of the older worker
- retirement income
- transportation

Each of these services is supplied both by government and through the market. Eligibility for government programs may depend on age alone; age and income; age, income and disability, or even other combinations, each corresponding to a distinct program with its own source of funds. It is a problem that an individual who needs a battery of services may not qualify for all of the independently authorized services in the battery. Nor can it be assumed that people who do not qualify for public programs can purchase the equivalent services privately. Some services are too expensive for all but the very rich, yet are not available as a matter of right even to poor persons who need them. Finally, even those government services for which an individual qualifies may be in short supply, dispensed only on a first-come, first-serve basis, or perhaps rationed according to need.

The long term care of last resort is the nursing home. It is possible that gaps in the community based long term care system are tolerated because standing behind that system is the nursing home. Nursing home care is so expensive, however, that many older people exhaust their personal resources when they under-

take to purchase it privately. Thus pauperized, they qualify for public financing of their stay, but this comes only at great personal cost, psychological as well as monetary, to them and their families. As the society ages, and functional disabilities become more prevalent, these costs will be borne by increasing numbers of families. It is far from clear that this is how the society wants to arrange its future long term care.

This study addresses these questions as they arise in Chicago. The size of the elderly population of Chicago will not show any increase over the period 1980-2010; only after that will the number of elderly in Chicago begin to increase significantly. In the two succeeding decades, however, the size of its city's elderly population can be expected to increase substantially, placing an unprecedented strain on the entire local long term care system. Between now and then, and especially by the turn of the century, there exists the opportunity to restructure the system so that it will be able to supply its vastly expanded pool of clients with the services they need in order to thrive. Correcting present deficiencies will lay the groundwork for meeting future need.

CENTRAL QUESTIONS OF STUDY

In surveying the present long term care system, this study has sought to answer three central questions.

1. How can the social service and health care systems assure that individuals will function as independently as possible?
2. How do we assure that the elderly have access to appropriate combinations of service?
3. How can we ensure continuity of appropriate combinations of service as the needs of the individual elderly person change?

INDEPENDENT FUNCTIONING

This study starts from the premise that independent functioning and living is the normal situation for those over 65. It should be the individual's and society's goal to preserve that independence for quality of life reasons and, probably, for economic reasons.

The functional disabilities of old age require affected persons to change their ways of interacting with their environments. Sometimes they must interpose a new implement between themselves and their environment: a wheelchair, a cane, a hearing aid. Sometimes another person must be interposed, a housekeeper, for

example, or an entire institution such as an adult day care center. Most of these changes involve diminished as well as altered interaction with the environment. Occasionally the implement that is interposed so alters the interaction between person and environment that the implement takes the place of the former environment. This is what a nursing home may do to a patient during a long stay. Individuals maximize their independence in functioning by maximizing the amount of interaction between themselves and their environment that does not need to be mediated by new implements. In practice this often means individuals maximize their independence by staying out of nursing homes (except for short term recuperation), but in order to do this on a large scale community based services will have to be expanded and systematized.

ACCESS

Access to the appropriate combination of services will maximize independent functioning in most cases, of course, but the questions of access, and of access to the right services, deserve treatment in their own right. Informal support systems, involving the donation or exchange of services among family and friends, are often considered the best for many purposes. A spouse, less disabled, or differently, often supplies most of the long term care required by the mate. Similarly a grown child. Informal support is no panacea, however. Many elderly persons have no spouse, or other relative or friend, on whom to call. In addition, informality can easily conceal abuse. An abuse itself may be fostered by the strains of caring for a disabled elderly friend or relative. Further, although informal services are rendered outside the cash economy they are not "free". The supplier makes an unreimbursed expenditure of time and effort, and if that person would otherwise participate in the labor force, the economy as well as the caregiver is losing that person's value in the cash economy.

Problems of access multiply as services become more formal. Whether the source of supply is the market or the government or elementary, the right services must be offered in the right place in a manner that allows the intended recipient to access and make proper use of them. If a service is supplied only through the market, then monetary resources are a prerequisite to access. And if a service is supplied publicly or charitably, only those who satisfy the requirements of the program or programs have access to the services. In short, access appears problematic, even for people whose need is manifest.

CONTINUITY OF CARE

While chronic conditions underlie much disability among the elderly, these conditions are punctuated by acute episodes and/or abrupt changes. It is taken for granted, in theory if not always in practice, that patients should be supplied with increasingly intense medical care as an episode grows increasingly acute.

It is less well understood that a long term care system must facilitate analogous movement through the stages of recovery, helping the individual eventually to assemble a set of services appropriate to his or her stable condition. The obstacles to this kind of continuity are not limited to problems to access. No client can be expected to know the full range of suitable services. Locating the right services and bringing the client into contact with them should be part of the job of the caregiving organizations with which the client is already in contact. Continuity of chronic as well as acute care can also be facilitated by case management supplied as a distinct service. A professional case manager monitors the care that an elderly person is receiving and recommends appropriate transitions as the person's condition or circumstances changes. However the most profound discontinuities of care may be precipitated by loss of the services of a spouse or other informal caregiver and thereby escape the attention of the formal caregiving system. Cases like this raise questions about the system of preventive care and outreach services.

BASIC ASSUMPTIONS OF THE STUDY

The three central questions of the study reflect concerns with independence of functioning, access, and continuity of care that are rooted in 12 basic assumptions to which the study is committed.

1. Health and social services should strive to maximize the independent functioning of the individual.
2. Care should be placed in the least restrictive setting consistent with patient choice and needs.
3. There will be a large increase in the number of elderly persons requiring institutional and non-institutional long term care in coming years.
4. Geographic, financial, organizational and psychosocial barriers presently appear to prevent individuals requiring long term care from accessing appropriate levels of care.

5. There is a potential for movement of long term care consumers through varying levels of care in a manner whereby individuals would be served in the least restrictive and least costly non-institutional settings appropriate to individual needs.
6. The availability of appropriate long term care resources should be increased and/or maintained as needed, to allow for the movement of individuals to appropriate level of long term care.
7. The desired long term care system should include suitable non-institutional services and should provide a mechanism for assessment of client needs to ensure referrals to the most appropriate form of service.
8. Long term care facilities should develop working relationships with providers of non-institutional services available in the community to insure smooth transition of patients to various services within the system.
9. Government often must serve as a financial backstop for long term care consumers with limited capability of purchasing needed care. As a result of its role in regulation and funding, government actions impact significantly on the availability of services and quality of care within the long term care system.
10. Funding and reimbursement mechanisms should be established in a manner that encourages an equitable distribution and optimum use of existing facilities; while adequate capacity must be maintained, excess beds of all types must be discouraged.
11. There may be inappropriate use of institutional services as a result of insufficient availability of non-institutional long term care services.
12. Effective and valid assessment instruments and monitoring techniques employed in a reliable manner are essential in appropriate placement and maintenance, program evaluation and cost efficiency in long term care services.

IMPLICATIONS FOR PLANNING FOR THE CITY'S ELDERLY

Running through the 12 assumptions is the view that all those who need long term care services should receive them: the right kinds; in the right amount; at the right times; in the right manner; and in the right settings. In attempting to plan and

provide for a growing number of elderly individuals with functional limitations, it is therefore important to consider a wide range of traditional, institutional and alternative, non-institutional options available in the delivery of long-term care services. In shaping its system of long-term care, society will likely make tradeoffs among scarce budgetary resources, taking into account existing efforts to address these needs, institutional commitments to current efforts, the availability of more cost efficient service arrangements, and our perception of the nature of the needs to which we are responding. In order to fashion a coherent system of long-term care services, planners will need a logical set of operationalizable goals and objectives, as well as a clearly defensible rationale. Translating goals into rational and attainable objectives will require clear understanding of both the service needs of the elderly and the make-up of the provider environment. This is what this plan begins to do for Chicago.

ORGANIZATION OF THE REPORT

Following this introductory chapter, the report will present demographic context and projections emphasizing functional disability, morbidity, and mortality among the elderly. The report will then devote one section each to fourteen long-term care services.

These sections describe the present service system, assess its present adequacy, project the magnitude of the need for the service to the year 2000, and recommend changes that would help the system to meet the projected need. Present and future need are estimated from demographic predictors of functional disabilities in activities of daily living.

One section discusses housing for the elderly. It shows that the adequacy of housing for the elderly involves much more than its being decent, safe, and sanitary. It is the locus of the provision of or access to the health and social services comprising most of long-term care. The nursing home, or perhaps the life care retirement community, is where long-term care services are most concentrated. But any house can be supplied with a large battery of in-home services.

Several of the services, taken together, stand as the community-based alternative to nursing home care. One section focuses on services that help the elderly compensate for inability to perform simple personal tasks such as getting dressed, or household tasks such as cooking and/or planning meals and house cleaning. The need for these services implies the absence of a fully competent caretaker in the household. Even where such a household member is available, however, the impaired elderly person may

benefit from or even require services such as adult day care, which is rendered in centers rather than in the home. This is the subject of another section. The time that the impaired individual spends in the day care center also supplies the household caregiver with a respite. Then the focus shifts to the most medically intense of the in-home services, home health care. This is rendered by a registered nurse or therapist as part of a course of treatment aimed at rehabilitation or recuperation. It may but need not be preceded by in-patient treatment in an acute care hospital, and can be supplied along with less intense in-home services such as those discussed in chapter five. Like home health, the medical component of another alternative service, hospice care for the dying, is rendered largely by nurses, mostly at the patient's home. There is also a section that discusses the nursing and social services that hospice includes, depicting it as a small but growing alternative to institutional care.

The effectiveness of community based alternatives to institutional care can be increased by such supplementary services as congregate dining, transportation, education and recreation, and employment. Taken singly, none is essential to independent living, but in the aggregate they may often tip the balance. While seniors' access to education and recreation, as well as employment, may be expanded with the use of a little imaginative programming, current programs of transportation and congregate dining would be used more if they were adequately funded.

The discussion of individual long term care services includes a treatment of nursing homes, that form of housing in which social and health services may be most concentrated. It is clear that the need for this service remains great, at least in the absence of a more ample supply of in-home services. As concerns the irreducible minimum of patients who will always require this level of care, the quality of nursing home care available, as well as the pauperization imposed on so many, are pressing issues.

One inappropriate reason for placing a person in a nursing home is mental illness. While a few chronic, progressive mental illnesses require custodial institutional care, most mental illness among the elderly can be treated on an outpatient basis, although funding, supply, and manifest demand for these services are currently low out of all proportion to need.

Two of the sections are about conventional medicine, primary and hospital care respectively. They reveal a great capacity to treat acute conditions of the elderly, a lesser capacity to treat chronic conditions, and very little awareness that treatment of non-terminal episodes should equip the long term care patient to use the long term care system to live as satisfying a life as possible.

The report concludes with a chapter which develops recommendations out of the findings of the preceding material. Underfunded and fragmented, the present long term care system of Chicago is ill equipped to meet the explosion of need that is likely to burst on it in the second decade of the next century. Even before then society will be faced with an unprecedentedly large proportion of very old, poor persons, many of them minority women, living alone, lacking access to informal care. At the same time, the ratio of dependent to independent persons will be unusually high; raising public monies will be difficult. Without proper planning in the present, the society could easily "solve" its future problem by increasing the supply and reducing the quality of publicly financed nursing homes. With proper planning new institutions can be established that will overcome fragmentation and spread the burden of payment over more people and a longer time. Mandated linkages, case management and a universal funding source like long term care insurance should occupy a central place in a redesigned system.

CONCLUSIONS AND RECOMMENDATIONS

In the second decade of the twenty-first century the elderly population of Chicago will embark on a rapid twenty year expansion that will generate a greatly increased need for long term care services. Between now and then, however, the need for long term care services will increase only slightly. Nevertheless, with current need already outstripping current supply in a system plagued by problems of access, there is no cause for complacency. The pressing task in this interim quarter century is to upgrade the long term care system in such a way that when the time comes, its rapid expansion will take place along lines that the citizens of Chicago will have chosen deliberately. This study attempts to draw lessons from our current long term care experience and apply them to that planning task.

The principal lesson can be seen in the way this report is organized, service by service. The current long term care system is deeply fragmented along service lines. Eligibility for one service does not confer eligibility for a complementary service or, in the case of an acute episode, for follow-up and succeeding services. This is true even of in-home services, which, taken together, form a relatively homogeneous group. As a result access to care is often restricted and continuity of care disrupted.

Fragmentation means that there are multiple, mutually independent sources of service, each one aimed at meeting part of an individual's need. Fragmentation means that because no single source of service is responsible for ascertaining that all of an individual's needs are met, some needed services may be unavailable or inaccessible to a given individual. The community based long term care system is organized on the assumption that an individual's affliction can be treated with a narrowly defined and precisely administered service. The client's underlying condition is assumed to be robust, so that once the discrete affliction is cured or compensated for, the client can resume normal activity. This view of the client, however, bears little relation to the elderly person who needs the long term care services that have been discussed in the preceding pages. The client of long term care is typically afflicted with chronic conditions that impair functioning and intrude on the client's life in ways that may vary according to his or her social circumstances and emotional condition. Appropriate countermeasures may not fall neatly under the definition of a single service or under the aegis of a single provider. It is by no means certain that the current service system will assemble the right set of services for any given client.

A multitude of funding sources stands behind the multitude of services: Medicare; Medicaid; The Older Americans Act; the Community Mental Health Act; and the Illinois General Revenues. Each of these determines its own priorities irrespective of the priorities of the others despite the interdependence of their impacts on the client. It is these funds that elicit the supply of services that are available to clients. For example, a client whose arthritis qualifies him or her for home-delivered meals may yet lack access to the transportation that, because of a need for outpatient medical treatment, is equally essential to his or her independent living. In-home medical treatment under Medicare, which might offset the absence of transportation, is available to patients whose condition is unstable, but only to those patients. A patient who does qualify for these home health services, however, is also eligible for Medicare reimbursement for ancillary home health aide services. But when these are discontinued, as they must be with the discontinuation of the skilled services, there is no certain mechanism for maintaining or reestablishing the flow of such ancillary services when they continue to be needed. In such situations clients may find themselves without service, and/or providers may be tempted to redefine the client's need in order to force it to conform to the available service. Neither of these outcomes helps to optimize the allocation of resources, which is a task that requires coordination among diverse funding sources.

It is clear that several aspects of the organization and funding of long term care services contribute to the fragmentation of the system. Service-specific eligibility rules are a major problem as illustrated above. But even if they were abolished, problems would remain. It is possible to imagine a single, all inclusive determination of eligibility made by a professional who could authorize the provision of all appropriate services. Even in such a case, however, a client who needed to combine the services of several providers would be more likely to fall short of the full complement than would the client who could receive all of those services from a single provider. Further, even a single provider of multiple services might well fail to coordinate its own specialized units, thereby confronting clients with the same kind of problem that would obstruct their access to necessary services that were scattered over several specialized providers. Fragmentation is thus the product of: 1) the internal complexity of the service system, whether that system is contained within a single organization or spread among many; combined with 2) disparate eligibility rules that grow out of independent funding sources. The consequent inaccessibilities, discontinuities, and unavailabilities have manifested themselves repeatedly through the pages of this report, often in the company of assertions of the need for greater coordination.

Coordination can be supplied on a client-specific basis by case management. The functions of case management in a system of long term care include collaborating in arrangements to assure continuity of service regardless of the auspices of the provider, making necessary care arrangements, referring and coordinating appropriate service, arranging for covered items and services, maintaining a continuous relationship with the individual, being a broker by matching individual needs and resources, and insuring delivery of services. This definition is "based on the fact that long-term care individuals usually have more than one need and must have contact with more than one provider. It reflects also the fact that these needs are chronic and continuous, rather than random and episodic; hence the need for case management over time."¹

A good case manager is an invaluable asset to clients. By assuming on-going responsibility for selecting and securing the needed services, the case manager, acting for the client, absorbs much of the adverse impact of fragmentation. The case manager assumes what would otherwise be the client's responsibility for coordinating the service system, assembling what is probably a better battery of services than could the client acting on his or her own behalf.

In Chicago, the Department on Aging and Disability (DAD) purchases case management services from three social service agencies, Catholic Charities, Lutheran Social Services, and United Charities. Case management is available to frail, homebound elderly who are receiving in-home services. In attempting to secure the particular combination of services needed by a client, a DAD case management unit follows a six step course.

REFERRAL. The client or his/her representative contacts the Department on Aging and Disability's Information and Referral Unit. If the client is screened as potentially in need of case management services, the case is referred to the Case Management Unit which serves his/her residence. In some prearranged situations, social services, health and other professionals are authorized to contact the Case Management Unit directly.

INTAKE SCREENING. A specialized intake case manager telephones the client to discuss the client's service needs within three days after the Case Management Unit receives the referral.

IN-HOME ASSESSMENT. Any client considered eligible for case management services is visited in his/her home within 30 days of the date of referral. During the visit, the

case manager conducts a thorough assessment of the client's needs and discusses possible solutions for meeting those needs.

SERVICE PLAN. Each client has a written comprehensive plan which brings together the services and supports he/she requires. A notification, sent to the client 15 days after the in-home assessment, summarizes his/her service arrangements and provides him/her with important names, dates and telephone numbers.

ONGOING CONTACTS. Ongoing contacts between the client and the case manager are an important part of case management services. Within sixty (60) days of the beginning of each service plan, the case manager contacts the client to make sure all of his/her services and supports are functioning effectively. In addition, every client is encouraged to telephone the case manager assigned to his/her case with pertinent problems, questions or concerns.

REASSESSMENT. Every client is reassessed within one year of the beginning of his/her service plan. Reassessments may occur more frequently if the client's condition changes and other service arrangements are necessary.

The DAD case management program departs from the generic description given earlier in only two important respects. First, DAD case manages all clients receiving in-home services through the DAD system, but only those clients. Since in-home services are in short supply, many persons who need case management services may not get them without a long wait. Although the very most impaired clients receive case management as an entitlement through the Community Care Program of the Illinois Department on Aging, Older Americans Act funds available to DAD are insufficient to meet the remaining need.

The case management service offered by DAD departs from the generic model in a second respect. Once the flow of services to the client has been established, the case manager initiates only annual contact, principally to reassess the client's condition. The case manager does try to use both formal and informal caregivers as informants to monitor the client's evolving condition and circumstances. Such informants can obtain and impart valuable information. It is not, however, all that a case manager needs to know about a client, and far from what a case manager does know if he or she remains in frequent contact with the client, as stipulated in the generic model. For this reason the DAD case management program is not designed to compensate for as many of the effects of fragmentation as it might if it had greater financial resources.

The OAD case management program does not purport to be a system-wide compensation for the effects of fragmentation. It is important to recognize this limitation, and important to observe that it reflects something that is both a strength and a weakness of case management. Case management is simply added to the existing service system. It does not alter the services. That makes it easy to introduce, especially on a small scale, assisting a subset of clients without disturbing the ongoing behavior of the established providers. On the other hand, case management only compensates for the absence of proper linkages among agencies and meshing of their programs. It does not produce systemic change. It is, in fact, an additional service, one that itself may have to be coordinated with others from time to time. In this sense no amount of case management can solve the problem of fragmentation.

If, when the number of functionally impaired elderly does increase in the next century, the resources available to the service system allow it to expand commensurately, expansion of the case management program will not, by itself, suffice to deal with fragmentation. In fact the expansion of the service system as a whole need not even exacerbate the fragmentation problem. It is true that additional eligibility rules and barriers to access would further fragment the system. But increasing the number of providers would offer clients more points of access, and similarly, would offer each provider a larger number of other providers with which to form linkages. It is as a supplement to a system of such bilateral linkages that case management can make its greatest contribution.

Linkages among provider units can not be counted upon to spring up spontaneously. The linkages that are needed will be forged only in response to explicit rules that require them. Such rules might be incorporated in reimbursement regulations for publicly funded services. For both public and private services, State and/or City licensure requirements could make linkages integral to the services regulated. Since the reason for mandating these linkages is to facilitate the communication of the case planning and assessment that should occur within provider units, this kind of service-specific case management should itself be mandated. Regulations that required service-specific case management and inter-service linkages would need some enforcement mechanism, including monitoring, evaluating, and influencing providers' treatment of clients. Since these activities are part of the job of comprehensive case management, it would be logical to combine the enforcement and comprehensive case management functions in a single organization. The resulting capacity for coordination could be exercised to ameliorate the fragmenting effects of multiple, service-specific providers. However, unless case managers gained the authority to override disparate eligibility rules, a major source of fragmentation would remain.

Fragmentation is not the only serious problem afflicting the long term care system of Chicago. Care is insufficiently available, as well. The unavailability of long term care has several causes. 1) Some services are underfunded by government. This appears to be true of in-home services such as chore/housekeeping, homemaking, and home-delivered meals, as well as transportation services, housing for the elderly, and adult day care. 2) Other long term care services are unavailable because of governmental restrictions on eligibility for the services. Home health care and many of the means-tested programs are made unavailable in this way. 3) Cost containment procedures which curtail the utilization of still other services are often intended to shrink the supply of those services. Medicare's use of increasing deductibles, co-insurance, and the DRG prospective payment reimbursement system is expected to force some hospitals to close. 4) Services that are purchased on the market will be undersupplied if their prices are too high for people who need them. This seems to be true of home nursing care, transportation, housing of many kinds, nursing homes, day care, and a variety of in-home services. 5) Much of the housing and in-home service that is supplied by informal caregivers outside the money economy depends upon formal supports like in-home service, adult day care, or home health. Curtailment of these formal services can thus undermine the supply of informal caregiving.

Adequate funding of long term care would alleviate many of the problems associated with both fragmentation and undersupply. Although appropriation by state and federal governments relying on broad-based progressive taxation is the best method of financing publicly needed services, insurance accomplishes some of the same things by dispersing the cost of misfortune among a large population only few members of which will ever require more than minimal reimbursement. A scheme of insurance that covered the cost of the full range of services would be a good instrument for funding long term care. This would be true of either public or private insurance. Either would tend to create a demand for, and hence a supply of, the services that were covered. In either case, also, the policy could be written to cover not enumerated services, but whatever services a professional judged appropriate for that client. The effects of fragmentation, thus, would be eased simply by adequate funding, and would be curtailed radically by coverage based on the client's need.

It is important to recognize that few proposals for what is often called "catastrophic health insurance" cover long term care, including the "Bowen Plan" proposed by the Reagan Administration. Proposed public catastrophic health insurance schemes usually cover the same services that Medicare covers, but cover only exceptionally high expenditures on them. While the deductibles and coinsurance required by Medicare grow very large

during an intense, prolonged acute episode, their direct impact is on the patient's financial condition; they do not cause the patient to postpone or forego services that are needed in the management of the illness. In this sense, catastrophic health insurance is irrelevant to long term care.

The costs of extended long term care and of catastrophic illness do have one thing in common among the elderly. They both result in very large personal outlays by many people who thought that Medicare would "pay the bill". Long term care and catastrophic illness are the two large gaps in Medicare coverage. If catastrophic illness should be insured against, so should chronic conditions and the costs of long term care.

Private long term care insurance, which can be written to cover both community based and institutional care, faces the problem that all voluntary insurance faces. Those persons most likely to buy it are those who have reason to believe that they will need to claim the benefits. Unless people who are relatively good risks can be persuaded to buy the insurance, the insurer is forced to set the premiums at levels high enough to cover the costs generated by the disproportionately numerous bad risks. High premiums, in turn, tend to repel all but the worst risks.

There can ensue a spiral of rising premiums and loss of the better risks, leaving the insurer with only poorer risks who consume benefits in large quantity, thereby necessitating another round of increases in premiums, and so on. These spirals defeat the basic idea of insurance, the pooling of good with bad risks. In long term care insurance the danger is that only the old and frail will be motivated to buy it, in which case the insurance might be set at a price high enough to trigger a spiral of increasing premiums and risks.

Long term care insurance policies that escape this fate often do so by limiting the benefits that they will pay.² None is anything like a universal funding source for long term care. Most limit coverage to nursing home care, perhaps with the addition of some home health service, but even these do not pay the full cost of the few services that are covered. For nursing home coverage, limitations typically apply both to dollars per day and to number of days (or, more often, years.) Limiting the dollar per day is especially burdensome to the resident in times of high inflation, for a payment that might have represented three quarters of an acceptable daily rate at the time the policy was purchased might cover no more than one quarter of the daily rate by the time the insured person was actually using the nursing home. If the out-of-pocket expenditures required of the insured were great enough to deplete that person's resources, that person would be forced to rely on Medicaid

for continued care. Similarly, a nursing home stay that exceeded the number of years of care covered by the policy would quickly proceed to exhaust many patients' resources and plunge them into dependence on Medicaid. Either of these cases would defeat the purpose of the insurance, namely to finance appropriate long term care services while preserving the financial underpinnings of the lives that those who are insured had lived prior to the onset of their chronic disabilities.

Long term care insurance might cover more of the cost of more services without setting premiums at excessively high levels if more people bought it when they were relatively young, that is, while they were still relatively good risks. Extending improved coverage to younger as well as to older persons would encourage those who had this insurance to seek appropriate in-home services at the very onset of functional impairments. Such early intervention would help to curb the effects and perhaps the progression of disabilities, and in all likelihood would also curb the total outlay of the insurance company. While younger people may not believe themselves to stand in great imminent risk of having to make large expenditures for their long term care, they might well appreciate the much greater probability that they could become good candidates for discrete early intervention services relatively soon. Younger people might well buy long term care insurance that offered full coverage of community based and institutional services for an actuarially fair premium.

If private insurance companies remain unable or unwilling to sell affordable, comprehensive long term care insurance, it should be offered by government, perhaps as an extension of Medicare. Although this might increase the cost to government, almost all of the increment would be produced by shifting existing costs from private individuals to government. (State government would also be relieved of a burden as funding shifted from Medicaid to Medicare.) Instead of burdening relatively few individuals with very large direct expenditures on long term care services, this scheme would require a great many individuals to pay small amounts of money at regular intervals in the form of payroll taxes or Medicare premiums or both. Payment into the necessary trust fund could also be supplemented by general revenue sources such as the progressive income tax.

Alternatively, long term care insurance could be organized as a mixed, public-private enterprise. The government could act as a reinsurer for private companies, thus further spreading the small risk of very large outlays. Alternatively, or in addition, the government could subsidize the premiums of private insurers. A premium subsidy might be coupled with governmental guarantees of some minimum profit, and heavy taxation of profits

above some maximum. Such an arrangement might be subject to re-evaluation after perhaps five years, by which time the industry would have been expected to have demonstrated either its viability or its permanent need for governmental subvention.

Any of the foregoing schemes could constitute a universal funding source for need-based comprehensive long term care. Such a funding arrangement, in addition to eliciting an adequate supply of long term care services, would allow clients' needs to be defined in terms of the functional impairments that required treatment or compensatory service, rather than in terms of the service for which the client might be eligible. The treatment plan would determine the services used rather than vice versa. Coupled with the expansion of case management and intake and discharge functions throughout the system, a universal funding source would do much to alleviate the effects of both fragmentation and undersupply.

Fragmentation and undersupply introduce extraneous influences on the distribution of services. If the system is to be reformed, it will require an authoritative method of ascertaining each person's need for service. The method must command wide assent so that it, and only it, will determine the distribution of services. Such authority will require prior agreement on definitions and indices of need, especially including the agreement of those who control funding and the determination of eligibility. It would make sense to vest such authority in a case manager.

One of the benefits of such an improved system of supply and distribution would be that preventive programs would become real possibilities. Services could be initiated for minor or incipient disabilities. Without the barriers posed by restrictive eligibility rules or by prices or copayments, use of the services for such minor problems would not be inhibited.

The value of this kind of intervention is twofold. First, as stated above, in a strictly medical sense diseases treated early may develop less seriously than others. This is especially applicable to the elderly, who are susceptible to complications arising out of acute episodes and their treatments. A second value of early intervention to offset minor disabilities among the elderly has to do with how individuals may adapt to the onset and development of a disability. In particular, an affected person who falls into a pattern of limited activity and social withdrawal may thereby undermine the informal support system on which many formal community based services depend. If that person's condition then worsens, community based services will be less than optimally appropriate, and perhaps not even practicable. Supplying such a person with transportation, in-home, and other enabling services may well reinforce the essential informal networks.

In comparison with such an integrated system, the fragmentation and underfunding of the current long term care system of Chicago become clear. Equally clear is the hardship they portend. Frail, low-income, minority elderly will grow in numbers, slowly until the second decade of the next century, and rapidly thereafter. The need for an ample supply of coordinated services will increase commensurately. The private market will not meet this need. Private providers do not set their prices low enough to create a market for preventive services. And at the prices that do prevail, neither can individuals purchase services to fill in the gaps in their fragmented or discontinuous care. The oldest old, who are the most likely to suffer from multiple chronic disease and to require multiple agencies are the most likely to suffer from any gaps or discontinuities that may exist in the caregiving system. Thus, the fragmentation and underfunding of the current system will become increasingly burdensome to the vulnerable elderly to whose needs long term care is supposed to be most responsive.

It is essential that the next decade be used to develop a system of comprehensive long term care, including both institutional and community based services, that ensures access to the right complement of services when they are needed.

Therefore we recommend that:

1. The federal government establish a five year program culminating in universal comprehensive long term care insurance available to all. During this time the government would promote and oversee the development of private insurance and would prepare a program of public insurance, for inclusion in Medicare, that would take effect at the end of the five year period if private plans did not then satisfy the need.
2. Medicare premiums, deductibles, and coinsurance for all covered services, including acute care hospitals, be reduced so that they no longer impede access to preventive care and early intervention. This could be done by relating co-payments and premiums to ability to pay, using a means test or sliding fee scale. Out-of-pocket expenditures under catastrophic insurance should be included in any such graduated system.
3. The State establish minimum standards for long term care insurance policy coverage and marketing practices.
4. City and/or State government establish a system of licensure of all long term care services. Licensure would require case assessment and inter-service linkages.

5. City government establish a case management and inter-service coordination function, and that it be combined with the monitoring and enforcement of licensure standards.

Until a comprehensive system can be fashioned and implemented, the existing system can be improved in many discrete ways. The service-specific sections of this report have formulated detailed recommendations on the basis of careful analyses. These are recapitulated below. They constitute an immediate agenda.

RETIREMENT INCOME

Traditionally retirement income has been based on pension, social security and savings/assets. The adequacy of this "three legged stool" of retirement income requires close scrutiny that includes a comprehensive review of the future roles of private pensions and of Social Security retirement benefits, of individual retirement accounts and other incentives for saving.

Pensions - Pensions require early, far-sighted planning of personal retirement goals and security. Millions of Americans do plan but for many more there is little or no planning. Pensions can also be a gamble. Some workers fall short of meeting stringent requirements. Others workers may unexpectedly lose some or all of their earned pension because of changes within their company.

We recommend Federal legislation:

1. to facilitate further private pension portability.
2. to give retirees greater control over the policies and management of their pension plans.
3. to improve enforcement of the Retirement Equity Act of 1984 in order to achieve fair treatment of women and minorities in the private pension system.
4. to improve insurance for single employee pension plans by increasing the premiums that they pay to the Pension Benefit Guaranty Corp. from \$2.60 to approximately \$8.50.
5. to prevent both internal and external "raids" on alleged surpluses in pension funds.

Social Security - The United States falls short of ensuring adequate income for all Americans. While Social Security has done much to reduce poverty and enable older Americans to plan secure retirement years, in the 1980s it has become the target of budget cutters who treat it as another expenditure rather than an essential component of the elderly's well being. That false notion may gain acceptance in the future unless Social Security is protected from destruction by political attacks.

We recommend:

1. Retention of the current cost of living allowance formula.
2. Adjustment of the fund to provide higher benefits for women.
3. Retention of all of the Social Security field offices.
4. Prohibition of use of the Social Security Trust Fund to balance the federal budget.
5. Making the Social Security Administration's budget an off-budget item.

HOUSING FOR THE ELDERLY

As Chicago plans to meet the long term care needs of its elderly population, it is critical to look at current and future housing needs. Many of Chicago's elderly population live alone and have physical limitations that prevent them from doing the most simple household tasks, yet they are not in need of institutionalization. If provided with a choice of housing combined with a mix of health and social services, this population retains its independence and can remain in the community, reducing the risk of premature institutionalization.

Funding has always been and will continue to be a major stumbling block in this area. The pursuit of financing for housing and related services will be difficult but not impossible. If implemented, the following recommendations would expand the range of housing choices for Chicago's elderly residents.

1. The Chicago Housing Authority (CHA) should expand its congregate housing program to all of its senior housing sites. Expansion of its congregate program should include at the very least, managers who are specially trained to work with the elderly, affiliation with a local ambulatory health care center or hospital for medical, nursing and social services needs, a meal program (at least one hot meal per day in a

a congregate setting nearby if not on site), coordination with the Department on Aging and Disability (DAD) case management system to seek out isolated tenants in need of services.

2. The CHA and DAD must seek out funding to finance and coordinate these services mentioned above.
3. Federal government must fulfill its primary responsibility for funding sufficient amounts of public congregate housing, and must supply the private sector with incentives to develop housing for the elderly.
4. The Illinois Housing Development Authority should receive additional funds earmarked for housing for the elderly.
5. The City of Chicago must re-evaluate zoning laws that currently prohibit accessory apartments, ECHO housing units and other housing options that are closed to Chicago's elderly population.
6. The Department on Aging and Disability, Department of Housing, American Association for Retired Persons and local advocates for the elderly must provide and promote shared housing and other alternatives in housing to elderly citizens.
7. The Department on Aging and Disability, the American Association of Retired Persons, the Metropolitan Chicago Coalition on Aging, and others should meet with the local Chicago banking institutions to explore ways to expand the provision of home equity loans to more banking institutions and to promote its use among the elderly.
8. Special tax incentives should be offered to potential developers in return for providing low-rental housing for the elderly. Additionally, the Department of Housing, and the CHA should explore the use of high quality, low cost pre-fabricated housing and locate a Chicago manufacturer for its production.
9. The Department of Planning and the CHA should examine the southwest and northwest sides of the City to identify sites for the development of senior housing.

IN-HOME SERVICES

The discussion of in-home services focuses specifically on nineteen different vendors who are currently providing either chore/housekeeping, homemaker and/or home delivered meal services to

the elderly population in the City of Chicago. The elderly clientele who are recipients of these in-home services fall basically in three different categories: (1) persons living in their own homes; (2) persons approaching discharge from an acute care facility; and (3) nursing home residents who could be discharged to the community if the necessary services were available. The services are funded under Title III of the Older Americans Act and out of Illinois General Revenues. Some of these monies are channeled through the State Community Care Program, a means-tested program which is designed to support community based alternatives to institutional care. Other avenues of delivery provide service on a first come first served basis to elderly persons in need of the service. During 1985 a total of 1,654 elderly persons received chore/housekeeping services from ten vendors for a total of \$1.5 million. A total of 867,360 home delivered meals were provided by three vendors to elderly persons at a cost of \$2.1 million.

Currently there is an acute shortage of in-home services, and there will be an increase in the need for in-home services between 1980 and the year 2000. The clients of in-home service are few in number, however, especially in contrast with the large number of functionally impaired elderly who might use these services. It is believed that many potential clients never make themselves known to the system. Many of those who do must endure waits of several months as they progress up the waiting lists.

We therefore recommend that:

1. an aggressive campaign of outreach be undertaken in order to find and bring services to all who need them;
2. funding for home delivered meals, chore/housekeeping, and homemaker services be increased by state and federal governments; and
3. the City of Chicago establish a consumer protection program to maintain the quality of and respond to complaints regarding in-home services.
4. the Illinois Department of Public Health and/or the Chicago Department of Health subject all in-home service providers to periodic inspection and quality of service review.
5. the fee for in-home services supplied under the Community Care Program be eliminated.

ADULT DAY CARE

Chicago has at least 11 publicly subsidized adult day care centers located in the city. Of the 11 centers, ten are considered as social models and one as a health model. Currently 369 elderly persons, ages 64 to 98 are enrolled at the eleven centers.

Of the 369 enrollees, 190 are black, 106 are white, 39 Japanese and 34 hispanic. The centers are attended by more females than males, 77% and 23% respectively. The centers have a combined daily capacity of 242 while their average daily attendance is 213. The client population comes from 35 of the 77 Chicago community areas. In terms of type of client enrolled at the centers, Alzheimer's disease victims are most common.

The 11 centers have been in existence on the average of approximately five years. The number of staff persons averages one to every five clients. In terms of client cost, 85 pay a daily fee without assistance, while 57 pay a copayment, and 227 attend free of charge.

As indicated by CHSA projections, between 1980 and year 2000, the adult day care population should increase. This increase accentuates the need not only for the public sector to make these services available and accessible to the elderly population throughout Chicago but for the private sector to develop them as well. Improved transportation to and from the centers is essential to making them accessible. Because the population is getting older and in need of more health oriented services, an increase in the number of health model adult day care centers warrants strong consideration. All adult day care centers, health or social model, should receive more formalized scrutiny from the State of Illinois.

We offer the following seven recommendations:

1. The concept of adult day care services needs to be more aggressively marketed to Chicago seniors and their families.
2. Financial incentives for the private development of adult day care centers should be identified and implemented.
3. The number of health model adult day care centers should be increased as the incidence of chronic, physically disabling conditions increases in the population.
4. Adult day care services should be extended to the northwest side of Chicago.
5. All potential clients of adult day care must have access to publically funded transportation. IDOT, CTA, and IDOA should supply the necessary funds.
6. As the number of these services grows, IDOA and/or DAD should consider adopting licensure standards, to assure quality services continue to be delivered.
7. Private employers should be encouraged to establish adult day care centers for their employees' elderly dependents. Government should subsidize these centers if necessary. In addition, this service could be included in employees' benefit packages and financed out of pension contributions.

HOME HEALTH CARE

Home health care refers to a core of health care services that are performed by nurses, trained home health aides, social workers, and professional speech, physical, and occupational therapists. Many home health agencies provide additional support such as durable medical equipment and nutritional assessment as well as the high tech services that some ventilator dependent and renal patients may require.

There are approximately 57 home health agencies serving the City of Chicago. Primary consumers of this service are the elderly who constitute the great bulk of the market for home health care. Costs for these services are borne almost exclusively by Medicare which pays about 23,000 claims per month in Chicago. The Medicare benefit allows for an unlimited number of visits to the homebound until the client has been stabilized. Many stabilized patients, however, may still need such services as physical therapy, speech therapy or the care given by a home health aide. Increasing numbers of claims are being denied by Medicare because they include service rendered after stabilization has been reached. In addition some providers are denying service to low income Medicare-Medicaid clients because of relatively low Medicaid reimbursement rates.

There appears to be a growing need for home health care in Chicago, extending beyond the current capacities of the existing reimbursement system. Projection of future need for home health care services indicates that the number of elderly persons requiring assistance in their recuperation will constitute almost half of the entire functionally impaired elderly population. Coupled with the fact that many elderly Chicagoans live alone without caregivers, this indicates that the need for home health care will be great. Efforts now need to be concentrated on expanding the Medicare benefit package.

We propose the following recommendations:

1. Congress should support by law the expansion of the Medicare home health benefit to allow for increased non-institutional, community based long term care services such as adult day care and chore/housekeeping services that allow the elderly to age in place.
2. The current definition of "homebound" under Medicare home health benefit should be expanded to include patients who are homebound except for trips to receive necessary treatment because the service can not be delivered in the home.
3. Medicare's home health policy regarding the treatment of stabilized patients should be re-evaluated and expanded to cover all of the services that are needed by patients whose condition has stabilized.

4. Medicaid home health coverage should be expanded along with the expansion of Medicare coverage so that it insures persons who cannot afford Medicare copayments. So that such dual coverage guarantees that home health providers will serve the low income elderly, the State must set Medicaid reimbursement rates high enough to cover the cost of delivering the service.
5. In order to expand its referral base and educate the consuming and providing public to the advantages of home health care, representatives of consumers, providers, and State and City governments should collaborate in the formulation and execution of a program of public education on the uses of home health care.
6. The Illinois Department of Health, Illinois Department on Aging and the Chicago Department on Aging & Disability should develop a reporting mechanism whereby consumers can report complaints and problems with home care agencies.
7. The Illinois Department of Public Health and/or the Chicago Department of Health should subject all home health care providers to periodic outcome based quality of service inspection and review.

CONGREGATE DINING

Chicago has a total of 105 community based dining sites located within the five DAD service areas. DAD is currently contracting with thirteen different vendors to provide congregate meals to the 105 sites. Although most areas of the City contain at least one congregate dining site, it is difficult to find host organizations in some sections.

We propose the following recommendations:

1. An aggressive campaign of outreach should be instituted, especially in low income communities, in order to locate all persons who need the services of the congregate dining program.
2. State and Federal governments should discharge their primary responsibility for funding the expanded program.
3. The Older Americans Act should be amended and sufficient funds appropriated under Title III-C explicitly to pay for the development and operation of congregate dining sites, in low income and other areas where scarce resources have made it difficult to establish sites.

TRANSPORTATION

Transportation is essential in getting people to services or services to people. It is often the glue that holds the elderly's fragile support network together. Transportation problems are complex and accessible transportation is an increasingly scarce resource.

We offer the following recommendations:

1. Efforts should be made to increase the CTA specialized service and CTA's role as a coordinator and broker of transit services for elderly and disabled persons across agencies and funding sources.
2. The CTA should purchase a number of lift-equipped buses to be operated on fixed routes for research and demonstration purposes in order to make intelligent decisions on the issue of dual systems.
3. Commuter rail stations in Chicago should be made fully accessible on a thirty-year phase-in schedule.
4. As special transit services are made available in neighboring suburbs, a system of coordinating routes and implementing transfers between systems should be established.
5. The Illinois Department of Transportation, the Section 16(b)2 grantor in Illinois, should accept responsibility for identification of the dollars spent and coordination of the programs offered for the elderly and disabled by multiple public and private sources in the state, including the Illinois Departments on Aging, Mental Health and Developmental Disabilities, Rehabilitative Services and Public Aid.
6. The CTA Special Services medical transportation program should be expanded to include transportation to social services such as adult day care. The Illinois Department of Transportation should finance the expansion.

EDUCATION AND RECREATION

Within twenty years Chicago's senior citizen programming will change. Seniors will resist being continually segregated from other generations on the basis of age. A broader base of academic programs will need to be available to satisfy growing educational needs such as that occasioned by second careers. Health and exercise facilities will provide special health club programs and memberships for older adults to answer the needs of a growing, healthier, health conscious older population. Volunteer opportunities will be more attractive for the recently retired. Support groups and clubs centered on specific interests, issues, or problems will need to be established to

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match the growing options available and the demands placed on older persons. Travel opportunities for older persons on low to moderate incomes will be in demand. Centers will need to change from havens in which to "pass away the time" to vital, bustling, mini-campuses offering a wide range of educational, health and recreational opportunities.

We recommend that:

1. The City Colleges of Chicago change its programming for seniors by
 - a. Reducing minimum class size
 - b. Reducing or eliminating course fees
 - c. Engaging in more extensive and aggressive outreach, especially to cultural minorities.
 - d. Assuring accessibility to program sites.
2. Museums develop programs for seniors, presenting them in communities as well as at the museum.
3. The Chicago Department of Cultural Affairs target senior participation as a key objective.
4. The Chicago Public Library develop and present programs for seniors as it does for children.
5. The Chicago Park District develop and conduct health and exercise classes for seniors, and adapt its facilities and programs to the increasing number of elderly persons in need of recreational opportunities.
6. The print and electronic media expand and concert efforts to keep seniors informed of opportunities available to them.

EMPLOYMENT OF THE OLDER WORKER

During recent years legislative changes have had a substantial impact on continued employment opportunities of older individuals.

It remains true, however, that many employers believe older workers to be relatively costly and thus hesitate to hire them. This denies many older persons the improved emotional and physical health as well as the financial benefits of remunerated work in old age.

We recommend that:

1. Employers sponsor education and training programs to give older workers the necessary skills to compete for promotions and advancements.
2. Employers provide in-service training for management and supervisory personnel on the characteristics of older workers to dispel widely held myths and stereotypes.
3. Employers develop employee investment plans designed to increase retirement income without increasing employers' costs.
4. Group health care plans for older workers be integrated with Medicare so that the health care cost for employees over age 65 would be picked up first by Medicare.
5. Employers discontinue spousal health coverage when such coverage is no longer needed, i.e., when the spouse has coverage or the spouse is deceased.
6. Employers offer a conversion of unused vacation and sick pay into a tax deferred annuity into which the employer and employee may jointly contribute.
7. Employers institute older workers' flex-time and part time employment, with proportional benefits at fair rates of pay.

NURSING HOMES

All patients in need of care should be able to find that care. Evidence is growing that some nursing homes are utilizing strategies to prevent patients receiving Public Aid from utilizing their facilities. Consumers' groups contend that those institutions that will accept Public Aid patients are often homes where the care and conditions are less than optimal. Part of this problem is due to both national and state level cost cutting policies, under which reimbursement for medical care for the poor is insufficient to pay for that care.

The increasing number of "old old" and elderly women will necessitate a more concentrated effort to provide care for patients in need of short-term skilled care, and also for patients with few personal financial resources, who often live alone or with an elderly spouse. With greater movement among levels of care, questions of continuity will take on increasing urgency. As more elderly patients receive short-term, skilled care and are discharged back into the community, the need for strong linkages between institution and community will become more pressing.

Therefore we recommend that:

1. Medicaid reimbursement approximate the actual cost of appropriate care. This will require revision of the reimbursement formula, perhaps to incorporate case severity weights.
2. Medical and ancillary staff of nursing homes improve and formalize their coordination with home health agencies and with other providers of community based care for purposes of discharge planning and follow-up care.
3. The City and State develop, enact, and enforce nursing home standards stipulating measurable outcomes of patient care.
4. The City of Chicago follow through on local sanctions for non-compliance by nursing home operators.
5. The City of Chicago encourage the State to follow through on enforcement of its nursing home standards, using sanctions and closures where necessary.
6. The Illinois Department of Public Health and the Chicago Health Systems Agency analyze bed need and its bearing on quality of care.
7. City and State address quality of care issues along the lines suggested by the Institute of Medicine:
 - a. End discrimination against Medicaid recipients;
 - b. Strengthen residents' rights;
 - c. Assure public access to inspection and cost reports;
 - d. Strengthen citizen and consumer advocacy; and
 - e. Design and fund an adequate inspection program.

MENTAL HEALTH

Current levels of training and experience of both health and mental health professionals in working with mental health problems of the elderly may be inadequate to provide elderly persons with appropriate psychological assessments. This in turn may have significant implications for: referral to appropriate mental health services; improvement in overall level of physical and social functioning; and the unnecessary utilization of institutional care. Current utilization data suggest that the elderly are significant underutilizers of outpatient mental health services and, with the exception of the nursing home industry, have probably been underserved by both public and private providers of related mental health services. Given the relationship between the presence of functional mental disorders and the need for supervision, social contact and assistance

with limitations in physical functioning and other mitigating factors; mental health services for the elderly should be coordinated under a more comprehensive continuum of health care which would include Home Health Care, Adult Day Care and In-home services. In addition, the role of relatives and friends in the lives of the elderly is very important, but while such relationships should be utilized to their fullest capacity, primary caretakers of the elderly should have access to supportive services as needed.

Therefore we offer the following recommendations.

1. Mental health services, like other long term care services, should be viewed in the context of a rehabilitation model, with a focus on the role of community based health and mental health services in assisting clients to maintain their highest level of social functioning.
2. Schools which prepare both health and mental health professionals should be encouraged to add courses and internships in gerontology to their curriculum, in order to assist professionals in their assessment and treatment of older persons with problems in daily living. Particular attention should be given to taking careful personal histories from the client and significant others to rule out possible organic and functional mental disorders.
3. Given the multiple needs of older persons with problems in daily living, community based mental health services should be coordinated under a more comprehensive model of community based health services.
4. Education and outreach programs should be developed to inform older persons and their primary caretakers of mental health programs and services which may be available to assist them.
5. The City of Chicago should support legislative efforts to increase reimbursements or direct grants for local, community based mental health services.
6. The City of Chicago should support current state efforts to provide specialized mental health services to those individuals in need of intermediate nursing facility care.
7. The City of Chicago should support legislation which would allow Medicaid to reimburse for mental health services provided by non-physician mental health professionals. In addition, the State of Illinois should require that mental health services provided by non-physicians be reimbursed under private mental health coverage.

8. The City of Chicago should support efforts to mandate State responsibility for community based mental health services.
9. Both the federal government and the State of Illinois should reaffirm their commitment to the provision of quality community based mental health services for the elderly by increasing and expanding coverage and financing for such services.
10. In the absence of increases in funding for mental health services by the state and federal governments, the provider community should pursue alternative delivery and funding possibilities which would allow for the provision of appropriate mental health services to this underserved population and their primary caretakers. Special attention should be given to supporting the development of self-help groups and therapeutic programs in other naturalistic settings.

PRIMARY CARE

Persons aged 65 years and older have a substantially higher than average number of doctor visits and hospital stays. In addition, chronic conditions are relatively prevalent among the elderly. These conditions tend to worsen with age generally. It has been estimated that at least 85 percent of all elderly have some chronic illness.

Many elderly prefer obtaining primary care services in the traditional manner--from office-based physicians. However, there are several drawbacks with this entry point especially when cost and continuity are considered. HMOs, on the other hand, appear to offer their Medicare enrollees care that is both less costly, and more comprehensive and continuous.

We offer the following recommendations.

1. The Chicago Medical Society, Illinois Medical Association, Chicago Nurses Association, Illinois Nurses Association and other professional societies must promote ongoing educational opportunities in gerontology for all health professionals who work or want to work with the elderly.
2. Chicago area hospitals that provide outpatient clinic services, along with COOH, DAO, and CHA should investigate innovative methods of delivering primary care services, including stationing health professionals in a variety of sites. This may include senior citizen centers, housing sites, churches and shopping areas.

3. Utilization of nurse practitioners and clinical nurse specialists as providers and extenders of primary care, especially in areas with documented physician shortages, should increase.
4. In addition to the federal program designed to attract physicians to Health Manpower Shortage Areas (HMSA), the Chicago Medical Society, the local medical schools, along with area hospitals should develop a plan to initiate service to these areas.
5. The Illinois Department of Education and Registration, with the collaboration of the Illinois Nurses Association, should compile an inventory of nurses by specialty, training and education, and setting. This will establish the basis for determining the optimum number of nurses (especially, nurse practitioners) for Illinois and see if there is a critical shortage of them.
6. CHSA should study quality and continuity of care in HMOs. Further, a legislative agenda should be developed that would advocate better incentives to HMOs to accept Medicare enrollees in their plans.
7. Because many people remain unfamiliar with HMOs, the Chicago Health Systems Agency, the Chicago Department on Aging and Disability, and the Chicago Department of Health should mount a widespread, aggressive campaign to explain HMOs to the public.

ACUTE CARE HOSPITALS

The 51 acute care hospitals in Chicago dispense a great variety of services that are especially relevant to elderly patients. Virtually all hospitals have some discharge planning capacity, and nearly as many offer social work services. One hospital in five has a home health care department. Other services are offered by fewer hospitals: skilled nursing care units, rehabilitation units, hospice.

Some services needed by the elderly are in short supply in Chicago: geriatric assessment units, formal hospital-based programs of services to nursing homes, follow-up care in nursing homes, osteoporosis prevention and treatment programs, and glaucoma retinal clinics.

The DRG prospective payment system recently instituted by Medicare makes it unprofitable for the hospital to keep Medicare patients in costly acute beds any longer than necessary. If Medicare patients are being discharged from acute care more quickly than they were, the issue that comes to the fore is

the adequacy of post-acute care. Hospitals' internal utilization review and quality assurance committees, as well as the federally designated Peer Review Organizations, are responsible for ensuring that patients are discharged at the appropriate time, not needlessly late, but neither before they have received acute care that prepares them adequately for post-acute care and recovery. Post-acute care is the responsibility of the hospital's own discharge planning. Discharge planners should help plan all hospital treatment of the long term care patient, so that it aims at allowing the patient to establish him or herself in the post-acute care long term care system.

Medicare does not pay all of the hospital bills of the elderly. Nearly four million dollars was spent in 1984 by Medicaid in Chicago to pay for those parts of hospital care of the very poor that Medicare did not pay. There is an indeterminate number of persons who are not poor enough to qualify for Medicaid but who cannot pay the deductibles and co-insurance left unpaid by Medicare. These people may postpone or forego hospital care, or even be denied service by the hospital.

We offer the following three recommendations.

1. Acute care hospitals should organize a comprehensive screening and assessment procedure for elderly patients which addresses not only acute-care needs of the elderly, but also post-acute needs.
2. Acute care hospitals should establish active discharge planning units that play a major role not only in discharging their elderly from the facility, but in admitting the patient, too.
3. Acute care hospitals' discharge planning units should develop a close working relationship with DAD's case management unit and with other providers of long term care services in order to ensure continuity of care for Chicago's elderly population.

HOSPICE

Hospice care is a new and unique type of service provided to the terminally ill at home or when necessary in an inpatient setting. Hospice provides relief from the symptoms of the final stages of disease in an environment that is supportive physically as well as emotionally and spiritually.

Chicago currently has five hospice programs covering approximately 93% of the city. Critical to that coverage is the core of volunteers and pastoral care to each hospice patient and

family. By assuring that a large pool of volunteers is available, the individual hospice is able to provide coverage to its service area.

Hospice programs are funded in a variety of ways; many are supported by grants and contributions. Few charge patients for direct services. Medicare will reimburse for related home health visits. Recently, hospice services were added as a reimbursable benefit under Medicare. Due to constraints under the conditions of participation only one Chicago hospice is Medicare certified. Nationally, fewer than 20% of all hospices elect to become Medicare certified.

The following recommendations address the issues of consumer and provider education, access to services and the utilization of community based linkages to assure continuity of care.

1. The percentage of Chicago residents with hospice services geographically available and accessible should increase from 92.5% to a level of 100%. It is anticipated that this will occur as the hospice programs follow a course of natural growth.
2. All hospices must provide professional education programs for physicians and other providers who are potentially capable of referring patients for hospice services, to encourage participation in and utilization of hospice services.
3. Similarly, hospice programs should actively implement a public information program designed to introduce the hospice concept. This recommendation would promote the use of hospice as an alternative for appropriate patients, increase its patient base and help to recruit a variety of volunteers in shortage areas.
4. All hospices must establish agreements with hospitals, home health agencies and nursing homes in their geographic area so that referrals can be easily facilitated. Likewise, hospitals and nursing homes should make referrals to hospices when appropriate.

Mr. AHRENS. The planning for the year 2000 focuses on long-term care, chiefly community based long-term care in Chicago. It focuses on a comprehensive and an integrated system on social, educational, as well as health services, focuses on basically the in-home services that can be community based, but it also does deal with institutional care. And there are some 100 recommendations for actions in the document, many of them, perhaps most of them here, for Chicago. But it asks for a comprehensive integrated system and it would have at least these components: acute hospital care, home health care, nursing home care, hospice care, affordable and accessible housing, mental health services, congregate dining services, more of our golden diner's clubs, chore/housekeeping services, home delivered meals, adult day care, life long education and recreational opportunities, employment and job training programs, accessible transportation, and adequate retirement income.

Focuses also on the important role of a case manager pulling all of these things together for an impaired person, and it focuses on the role of the Area Agency on Aging, my department is that, for the City of Chicago.

As I said, there are 100 specifications. Let me just briefly mention five. One, that the Federal Government should establish a 5-year program culminating a universal comprehensive long-term care for all; two, Medicare premiums, deductibles and co-insurance for all covered services should be reduced so they create no impediment to access the preventive care and early intervention; three, the State of Illinois should establish minimum standards for private long-term care, insurance policy coverage, and marketing practices (we are still waiting on that); four, City and/or State Government should establish a licenser system of all long-term care services, including boarding homes, which would include a requirement for case assessment and inter-service linkages; five, City Government should establish a case management and inter-service coordination function that is combined with a monitoring and enforcement of licenser standards.

Then we had six points that the report felt ought to be embodied in any kind of Federal long-term care legislature: one, voluntary enrollment; two, eligibility determined by the inability to perform two or more activities of daily living or the existence of cognitive impairments which require constant supervision, without regard to age, and without exclusions for Alzheimer's disease or AIDS victims; three, a broad range, as I mentioned, of institutional, community based and in-home services to be covered; four, rules, this legislation will be promulgated within 180 days of enactment so we don't have a Bill and nothing out because of the failure to come up with regulations; five, a distinct and central role for area agencies on aging, there are 13 of these in Illinois, in the coordination of a long-term care system; and last six, financing that spreads the cost of the program in an equitable manner to the general population in contrast to the financing arrangement found in the Medicare Catastrophic Coverage Act of 1988, in which the people over 65 are paying for everything.

And then lastly, on my own, I would like to endorse the ABC Medicare idea of my southern Illinois friend, Jerry Auerbach, who proposes that we reform Medicare so that Part A deals with hospi-

tals, Part B with medicine and doctors, and Part C for long-term care.

Thanks very much.

Senator SIMON. I thank you very much, Commissioner. I appreciate your comments and agree with you. You mentioned in addition to the long-term care, two other things. One is the lunch programs, you call them the congregate noon programs. For the record, I would say our audience is probably made up 80 percent of those over the age of 65. How many of you here, if you would raise your hands, participate in some kind of a program where noon lunches are provided at a reasonable cost?

OK. For the record, this is an audience of maybe 200 to 300 people, there are maybe 30 people who participate in the congregate noon programs. I happen to think these programs are extremely important. They are important, first of all, because those of you who live alone it is not much fun making a balanced meal for yourself if you are just living alone. Second, it is important to get out and to talk to others, to be at this kind of a meeting.

I know, even myself, if I am driving along in a car and I have the Medical Adviser on the radio and he says these are the signs of kidney disease, I think about it a little bit and by George, I have got kidney disease. If you are just living by yourself and only thinking of yourself, pretty soon you create additional problems. So I think those programs are extremely important.

Mr. AHRENS. That gives me the opportunity to say that this is the location of one of our golden diner's clubs, and some time around noon today there will be people eating in one of the adjacent rooms.

Senator SIMON. That is great. How many people do you serve all together in the City of Chicago?

Mr. AHRENS. Between 4,000 and 5,000 people at 99 different golden diner's clubs. This is a program that we pioneered in Chicago in 1968-69, and we have about 2,500 people who get home delivered meals each day, but that is because the City has a big chunk of money in that too.

Senator SIMON. But 4,000 or 5,000 out of a universe of how many?

Mr. AHRENS. There are close to 400,000—well, we would have to say of the age 60 population is eligible, close to 600,000 people in the City would be eligible.

Senator SIMON. So about 1 percent.

Mr. AHRENS. Right.

Senator SIMON. And I thank you very much, Commissioner. How long have you been Commissioner?

Mr. AHRENS. When the late Mayor Daley set up a commission for senior citizens in 1956, I wound up being one of the 30 volunteers on the board, and then in 1967 I became the Director. I did not serve in the Jane Byrne administration. But Harold Washington asked if I would come back. So fairly a long time.

Senator SIMON. As long as I can remember you have been the Commissioner, and I thank you very much for your leadership and for being here.

Jan Schakowsky who has been a real dynamo in this field. I am very happy to have you here, Ms. Schakowsky.

Ms. SCHAKOWSKY. Thank you. My name is Jan Schakowsky and I am Executive Director of the Illinois State Council of Senior Citizens, a coalition of more than 600 organizations, representing 250,000 senior citizens statewide, and in addition I am Coordinator of the Illinois Long Term Care Coalition.

Here in Illinois, as they are doing around the country, a wide range of organizations have come together under the banner of the National Long Term Care Campaign. Let's see some of those banners. I know there is actually some banners right here. OK, very good. Thanks.

Our goal is to urge Congress to respond to the crying need of families for help in providing long-term care for their loved ones. The Illinois Long Term Care Coalition is made up of nearly 50 diverse organizations, which together, represent millions of individuals. I have attached a list of those organizations to my testimony.

Today I want to focus on what Congress should do to protect American families from the potential devastation of chronic health problems. Our long-term care campaign is not currently supporting a specific legislative proposal, but we have agreed upon a set of legislative principles against which we will evaluate the many bills which are likely to be introduced. We offer these as a guideline for drafting an excellent bill.

I am going to highlight them now and I will attach a full copy of the principles.

First and foremost is the principle that long-term care services should be available to all who need them regardless of age or income, I repeat, regardless of age or income. The child with cerebral palsy, the father disabled on the job, the grandmother who suffered a stroke—long-term care is inter-generational. And help with long-term care is not just for the poor.

My mother died in a nursing home just over 2 years ago. My 83 year old dad, who worked from the time he was 12 years old, was paying at the rate of \$24,000 a year to the home. That is below average cost today. He had put money away, but it doesn't take a genius to figure out that had he lived longer his savings, and even his little home, would be gone. My family, of course, would have helped, but we are trying to put two children through college. Our story is repeated thousands, hundreds of thousands of times, millions of times across the country. All of us are threatened. All of us need help.

Second. A national long-term care program should be comprehensive, providing for services at home where most people would much rather be, in the community such as adult day care centers and institutional care such as nursing homes. We want services that maintain and enhance personal independence in the community and in the setting preferred by our loved ones and families.

Third. Financing. Where will the money come from? We believe that public funding is the only answer for the vast majority of Americans, and that the most sensible approach is to spread the financial risk for long-term care as broadly as possible, through a social insurance program similar to Social Security or Medicare. We favor sources of financing that are as progressive as possible, and we seek protection from out-of-pocket costs for low and moderate income persons. We believe that the public cost should be mini-

mized by building cost containment into the program. Poll after poll tell us that Americans are willing to pay more taxes for the security of knowing that their long-term care needs will be met. In our view, private insurance does not now and will not ever meet the national need for adequate and affordable coverage for long-term care.

Finally, the new program should assist families and other informal caregivers. Families and friends are serving as caregivers, as you have heard, not only because we have to, but also because we want to. But anyone who has provided that care, even for one week, even for one 24 hour period, knows the incredible physical and emotional toll that it takes. Families and friends should be an integral part of care coordination, and should have access to supportive services and training to facilitate their caregiving. The program should insure that the financial integrity and physical and emotional well-being of the family caregiver is maintained.

In conclusion, I wish to thank Senator Paul Simon for the leadership he has shown on this issue. The State Council of Senior Citizens and our National Council supported the Bill that you and Claude Pepper offered last session, the Long Term Home Care Bill, and we look forward to working closely with you in this new Congress. Thank you.

[The prepared statement of Ms. Schakowsky follows:]

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AFFILIATED WITH
THE NATIONAL COUNCIL OF SENIOR CITIZENS, INC.

THROUGH UNITED ACTION A BRIGHTER TOMORROW

CHICAGO, MARCH 13, 1989 - SENATE LABOR AND HUMAN RESOURCES
COMMITTEE

TESTIMONY OF JAN SCHAKOWSKY, Executive Director of the Illinois
State Council of Senior Citizens' Organizations and Coordinator of
the Illinois Long Term Care Coalition

My name is Jan Schakowsky. I am Executive Director of the Illinois State Council of Senior Citizens' Organizations, a coalition of 600 organizations representing 250,000 senior citizens statewide. In addition I am the Coordinator of the Illinois Long Term Care Coalition.

Here in Illinois, as they are doing around the country, a wide range of organizations have come together under the banner of the national Long Term Care Campaign to urge the Congress to respond to the crying need of families for help in providing long term health care for their loved ones. The Illinois Long Term Care Coalition is made up of 44 diverse organizations, which together represent millions of individuals. I have attached a list of those groups.

My testimony focuses on what Congress should do to protect American families from the potential devastation of chronic health problems. The Long Term Care Campaign is not currently supporting a specific legislative proposal, but we have agreed upon a set of legislative principles against which will evaluate the many bills which are likely to be introduced. We offer these as a guideline for drafting an excellent bill. I will highlight them now and attached the full copy.

1) First and foremost is the principle that long term care services should be available to all who need them regardless of age or income, I repeat, regardless of age or income. The child with cerebral palsy, the father disabled on the job, the grandmother who suffered a stroke - long term care is intergenerational. And help with long term care is not just for

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the poor. My mother died in a nursing home two years ago. My 83 year old dad, who worked from the time he was twelve years old, was paying at a rate of \$24,000 a year to the home. That's a below average cost today. He had put some money away, but it doesn't take a genius to figure out that, had she lived longer, his savings and even his little house would be gone. My family would have helped of course, but we're putting two kids through college. Our story is repeated thousands, hundreds of thousands of times, across the country. All of us are threatened. We are need help.

2) A national long term care program should be comprehensive, providing for services at home, where most people would much prefer to be; in the community, such as adult day care centers; and in institutions such as nursing homes. We want services that maintain and enhance personal independence in the community and in the setting preferred by our loved ones and families.

3) Financing: Where will the money come from? We believe that public funding is the only answer for the vast majority of Americans, and that the most sensible approach is to spread the financial risk for long term care as broadly as possible, through a social insurance program similar to Social Security or Medicare. We favor sources of financing that are as progressive as possible, and we seek protection from out-of-pocket costs for low and moderate income persons. We believe that public costs should be minimized by building cost containment into the program. Poll after poll tells us that Americans are willing to pay more taxes for the security of knowing that their long term care needs will be met. In our view, private insurance does not now and will not ever meet the national need for adequate and affordable coverage for long term care.

Finally, the new program should assist families and other informal caregivers. Families and friends are serving as caregivers, not only because we have to, but also because we want to. But anyone who has provided that care, even for one week, even for one 24 hour period, knows the incredible physical and emotional toll it takes. Families and friends should be an integral part of care coordination and should have access to supportive services and training to facilitate their caregiving. The program should ensure that the financial integrity and physical and emotional well-being of the family caregiver is maintained.

In conclusion, I wish to thank Senator Paul Simon for the leadership he has shown on the this issue. The State Council of Seniors supported the bill that you and Claude Pepper offered last session, the Long Term Home Care Bill, and we look forward to working closely with you in this new Congress.

THE LONG TERM CARE CAMPAIGN

ILLINOIS LONG-TERM CARE COALITION

List in formation 3/13/89

Access Living
 Alzheimer's Association
 American Association of Retired People, AARP
 American Association of University Women, Illinois Division
 Amalgamated Clothing and Textile Workers Retirees
 Amalgamated Senior Residence
 American Federation of State, County and Municipal Employees
 AFSCME Retirees
 American Heart Association of Metro Chicago
 American Nurses Association
 Center on Aging, Northwestern University
 Champaign County Health Care Consumers
 Chicago Department of Aging and Disability
 Chicago Gray Panthers
 Chicago Urban League
 Community Nutrition Network
 Gerontology Center, University of Illinois
 Governor's Office of Senior Involvement
 Guardianship and Advocacy
 Illinois Association of Area Agencies on Aging
 Illinois Citizens for Better Care
 Illinois Conference of Churches
 Illinois Council of Case Coordination Units
 Illinois Council of Home Health Services
 Illinois Gerontology Consortium
 Illinois Health Care Association
 Illinois Retired Teachers' Association
 Illinois State Council of Senior Citizens Organizations
 International Association of Machinists Retirees
 Little Brothers-Friends of the Elderly
 Marillac House
 Mental Health Association "Nursing Home Advocacy Program", Peoria
 Metro Seniors in Action
 National Council of Jewish Women
 Northeast Austin Organization
 Older Women's League
 Paralyzed Veteran of America
 Self Help Center of Evanston
 Senior Caucus of Jane Addams Center
 Senior Centers of Metropolitan Chicago
 Service Employees International Union
 Suburban Cook County Area Agency on Aging
 United Auto Workers Region 4 Retirees
 Urban League of Champaign County

THE LONG TERM CARE CAMPAIGN

LEGISLATIVE PRINCIPLES

American families are being stressed beyond their capacities because of the emotional and financial strains of providing long term care. A public program, which meets the following principles, is needed to address this family crisis:

1. Long term care services should be available to all who need them, regardless of age or income. Eligibility should be based on functional, cognitive or behavioral limitations, or the need for supervision because of risk to safety or health, or the need for support or training.
2. A national long term care program should provide a comprehensive range of facility-based and community-based health, social and support services. Services should be provided in such a way as to maintain and enhance personal independence in the community and in the setting preferred by beneficiary and family.
3. The financial risk for long term care should be spread as broadly as possible, through a social insurance program similar to Social Security or Medicare. The public program should provide a base of coverage for all.
4. The new public program should assist families and other informal caregivers. Families and friends should be an integral part of care coordination and should have access to supportive services and training to facilitate their caregiving. The program should ensure that the financial integrity and physical and emotional well-being of the family caregiver is maintained.
5. The new public program should be supported through sources of financing that are as progressive as possible.
6. Protection from out-of-pocket costs for low and moderate income persons should be provided.

7. The program should ensure high quality and access to care for all. A strong, independent care coordination component should be a central feature of the program. Paid caregivers should be carefully screened and well-trained, with wages and benefits commensurate with the substantial demands and responsibilities of caregiving. The payment system to providers should be structured to ensure quality of care and cost containment.
8. Cost containment should be built into the program. The public costs of the program should be minimized while meeting consumers' needs.
9. The program should allow for phasing-in to ensure orderly development of the new system and all of its services.
10. The states should be encouraged to be innovative and flexible in administering and delivering long term care services. Research should be conducted on the adequacy of services to meet family long term care needs and on more accurate measures of disability.

WHAT IS **THE LONG TERM CARE CAMPAIGN ...?**

The Long Term Care Campaign is a coalition of more than 100 national organizations dedicated to enacting comprehensive legislation to protect American families against the devastating costs of long term care.

The organizations participating in the Campaign reflect the diversity of America. They represent religious denominations, business, organized labor, veterans, women, the elderly, racial and ethnic groups, the disabled, youth, consumer and grassroots organizations. Together, the combined memberships of these organizations include more than 60 million Americans.

The Long Term Care Campaign has emerged in response to the tremendous outpouring of concern expressed by American families who are struggling with the emotional and financial stresses of long term care. The Campaign provides an opportunity for families to express these concerns to their elected representatives and to press for a comprehensive, national solution.

Campaign Goals

The long term care crisis is now a priority on the nation's political agenda. The Long Term Care Campaign is committed to enacting a solution that is comprehensive and available to all who need care. Services should support family caregivers, who now provide the overwhelming majority of care. And, the financial risk for long term care should be spread as broadly as possible, through a social insurance program that is paid for by all Americans and that assures access to care for all.

The Campaign has developed a set of legislative principles which will guide its efforts (see attached). We are not now taking positions on specific bills. But, participants in the Campaign are encouraging Members of Congress to cosponsor any or all of the bills that conform to the Campaign's principles. At present, several bills have been (or will be) introduced in the 101st Congress that are generally consistent with these principles.

Campaign Activities

In addition to the efforts of the Campaign's national organizations, state and local coalitions are organized in 26 states. These are: Arkansas, California, Connecticut, Florida, Illinois, Iowa, Kansas, Maine, Massachusetts, Michigan, Minnesota, Montana, Nebraska, New Jersey, New York, Ohio, Oklahoma, Oregon, Pennsylvania, Rhode Island, Tennessee, Texas, Vermont, Washington, West Virginia, and Wisconsin. Participants in these coalitions mirror the organizational memberships of the national campaign.

The first stage of the Campaign points the spotlight on the critical role of family caregivers in long term care. As a first step, state and local coalitions are inviting Members of Congress to be a "Caregiver for a Day." These events are designed to educate elected leaders and the public about the needs of caregivers and to highlight innovative programs for supporting caregivers who are struggling to provide long term care.

Subsequent stages of the Campaign will also focus on the needs and special role of family caregivers and on the need for a comprehensive program to meet family needs.

Printed materials and a video are available for use by groups for public education. For further information contact the Long Term Care Campaign at (202) 737-6340.

THE LONG TERM CARE CAMPAIGN...THE CAREGIVERS

FAMILY CASE STUDIES

Dixie Shilson, daughter
Chicago, Illinois

My name is Dixie Shilson and I live in Chicago, Illinois. My mother passed away in 1983 at the age of 74, after suffering from emphysema and brain cancer for 5 years. While she was alive, she repeatedly said to me, "Promise me you'll never put your father or me in a nursing home." I kept my end of the bargain and took care of her until her death. Even while working full-time as a restaurant manager, I gave up all my free time to take care of her.

Things have been just awful since my mother died. She left no assets but had accumulated a \$7,000 debt. Because my father was already showing symptoms of Alzheimer's disease when she died, I, the eldest of 5, took on the full responsibility for her debts. As a result, I was forced to declare bankruptcy in 1983.

For the past 5 years, I have taken the sole responsibility of caring for my 79 year-old father, who is now in the advanced stages of Alzheimer's disease. I recently moved from Oklahoma to be closer to my sister, who offered to help ease the financial burden. She and I clean houses during the day so that we can supplement my father's income of \$930-a-month from Social Security and his pension. My sister and I make around \$340 a week. With this money we are able to pay the \$950-a-month cost of 32 hours a week of home health care for my father. We are just barely able to meet the costs of rent, food, prescription drugs, health insurance and other essential items.

As you can see, I spend all of my time either working or taking care of my father. My sister and I clean houses as quickly and efficiently as we can, so that I can get back to relieve the home health aide -- home health aides are too expensive for us to keep any longer than is absolutely necessary. When I'm not cleaning houses, I spend my time dressing, bathing, feeding and walking with my dad.

I have dedicated the last 10 years to caring for both of my parents. Now, I am just too tired and don't know if I can continue to keep my promise to my mother. We need more home health care, but we just can't afford it.

I'm not bitter. After this is over, I'm going to be a volunteer for families with Alzheimer's disease victims because I now know first-hand what Alzheimer's can do to the whole family. I'm a mother and a grandmother and I know my children and grandchildren have felt the effects of my dad's illness.

My family situation is not an isolated case. I know there are other families like mine throughout the country who have sacrificed so much for their family members. We are not asking for welfare but we are asking that some assistance be provided so that we can keep our loved ones at home as long as possible. If I could have it my way, I would keep my father at home and keep that promise I made to my mother so many years ago.

Angie Bachschmidt, mother
Washington, D.C.

My name is Angie Bachschmidt and I'm from Washington, D.C. My youngest son, Robert, suffers from muscular dystrophy. He's 4 years old. He has a severe form of muscular dystrophy that is congenital and has kept him in and out of the hospital intensive care units for 2 years of his life. While in the hospital, he was placed on a ventilator to save his life. Because we realized that Robert would probably need ventilator assistance for the rest of his life, and we so desperately wanted him home with us, his father and I approached the staff of Children's Hospital of the King's Daughters in Norfolk, Virginia, where we were living at the time, about the feasibility of caring for Robert at home. We were informed that neither the hospital nor the State of Virginia had the necessary resources to properly care for Robert at home. In desperation, we approached other hospitals outside the area. Philadelphia Children's Hospital turned us away; so did Bethesda Naval Hospital. Finally, in April, 1984, Children's Hospital National Medical Center in Washington, D.C. accepted Robert as a child to receive home care.

My husband is a first-class engineman in the Navy and through the Navy, we are covered by CHAMPUS health insurance. When Robert was accepted at Children's Hospital, the Navy graciously granted us a humanitarian transfer to Washington, D.C. At the time of our transfer, CHAMPUS approved Robert's home care and agreed to pay for his medical costs. Then we got unsettling news. CHAMPUS would pay a maximum of \$1,000 per month for home care expenses. This amount would not even cover the rental costs of Robert's equipment, not to mention the needed supplies, nursing care and the other resources necessary to ensure quality care at home. Despite our attempts to reason with them, CHAMPUS refused to cover our expenses. Robert remained at Children's Hospital, where his expenses for 18 months of hospitalization totalled \$865,800. Home care for this same period of time would have been approximately \$90,000 -- nearly one-tenth of the cost of hospitalization.

In an unsuccessful attempt to get access to home care, our family had moved from Virginia to Maryland, where we heard the chances were better. Again, in hopes of having Robert home with the family, we had to move to Washington, D.C. We were told that with special permission, Medicaid would cover expenses for home nursing. Finally, in January of 1985, Robert came home.

Robert has received home nursing care for 2 years. CHAMPUS pays for most of Robert's supplies such as the respirator and catheters, as well as equipment needed to clear his lungs. Even so, many of Robert's needs go unmet. He does not receive any physical therapy, occupational therapy or speech therapy because these are not reimbursable by CHAMPUS or Medicaid. I am responsible for the costs such as increased utility bills, transportation, and other additional costs. I wish my family could get assistance in dealing with the stress of caring for technology-dependent children, either in the form of respite care or social work and counseling. Unfortunately, such resources are not available. I am left alone to pull all the necessary resources together and figure out how to pay for them.

Saving a child with modern technology is a blessing. Being at home with his family has made a wonderful difference for Robert. You wouldn't believe it's the same kid who was in the hospital. They say children who have been trached [have had a tracheotomy] can't talk, but he talks. He laughs and smiles and will kiss you.

I think families should have the right to care for their children at home, regardless of the state they live in and who's going to pay the bills. Having a chronically ill child is difficult. At least families should be given the help they need.

Virginia DiManna, wife
Germantown, Maryland

My name is Virginia DiManna. Seven years ago my husband, Daniel, and I had just seen our youngest daughter married, and we had only one more child left in college. Daniel and I were anticipating the great relief that comes with the satisfaction of knowing that all four of our children were on their own and that we finally would see the end of the heavy financial obligations of putting four children through school.

But today, I am disabled and out of the work force; my husband suffers from Alzheimer's Disease, and without some assistance, my husband may be forced into a nursing home and we will end up on welfare.

Seven years ago, Daniel and I lived comfortably on a combined income of \$70,000. We were relatively worry-free. We went camping often, and made plans for major trips. We also felt secure because we had prepared for our later years in retirement. We had set aside a substantial sum of money in investments and paid for what we thought was a good, solid insurance plan.

Seven years ago, however, something else happened, and it was major. My husband was diagnosed as having Alzheimer's disease.

Daniel is a graduate of Brown University. He is bilingual, he speaks Italian fluently. He has a graduate degree in banking and spent a lifetime working in the banking field in the State of Maryland.

Back then, we didn't know what to expect when the doctor said "Alzheimer's," but we know today. Daniel's disease has slowly taken its toll in most areas. He cannot write his name or dial a phone, and he hasn't driven a car in more than 5 years. He is unable to cope with the most routine parts of his day. He can't dress himself, can't deal with curbs along the street as he walks, he doesn't remember how to get in and out of a car. He is a danger to himself, and, particularly in the last 6 months some things have deteriorated quite quickly. He sees, but he does not know what he sees or how to deal with what he sees. He has also become paranoid and is increasingly verbally aggressive towards me. He knows me - but not on an emotional level - he sees me as his caregiver and nothing else. That hurts sometimes, but he doesn't know what he is saying.

I myself have problems to deal with. I left my teaching job of over 30 years on disability with loss of visual function and

degenerative osteoarthritis. My ability to handle the physical care of my husband has been a challenge, to say the least. My arthritis has significantly worsened and in 1983 I was diagnosed as having angina. I was told that angina was the result of stress, the byproduct of caregiving for an Alzheimer's patient. I live the "36-hour day" you hear about. I give my all in caring for my husband.

But what I do is important. Alzheimer's has robbed my husband of his mind. I don't want it to rob him of his dignity as well. He receives loving care - the kind only I can give - and I always try to protect his sense of human dignity. There will come a time when I will be physically unable to take care of my husband any longer, but until that day comes I will be there for him.

It is sad that our best laid plans of a lifetime have proven to be totally inadequate for dealing with our situation. The medical bills for Daniel and myself are significant. My husband goes to day care twice a week, so that I may spend one day helping my mother, who has recently broken her leg, and one day doing the things I need to do but can't do with Daniel in tow. Paying for health insurance, medical bills and day care expenses, on top of rent and food, I find income over expenses to be short about \$430 every month. Additionally, any time there is an extraordinary medical requirement, I'm even further behind.

We are getting by but we worry, for how long? We live on my disability retirement and Dan's retirement from the bank. With both of us being 61, neither one of us is eligible for regular Social Security. My husband, however, is now on social Security disability and on April 1, will be on Medicare. Unfortunately, Medicare does not cover the kind of care we need, custodial care. The insurance policies we so carefully chose don't help much either, because they also don't cover custodial care. Within the last 5 years, I have used up more than one third of our assets paying bills.

Daniel and I can look forward to ever-escalating medical costs and we can reasonably anticipate that the remaining two thirds of our assets will be gone rather quickly, as Daniel's disease progresses. We want to stay at home as long as possible; it's where we belong. I need some part time assistance at home to be able to continue to take care of my husband at home, and not force placement in a nursing home.

Nathan Mendelsohn, husband
Philadelphia, Pennsylvania

My name is Nathan Mendelsohn. My wife Rose and I were happily married for 49 years; she was my best friend and a great partner. We lived in Oxford Circle. I was a police officer for twenty years with the Philadelphia Police Department, and she took care of our house and raised our two daughters. She also worked for the State Department of Vital Statistics.

After Rose had a stroke in 1982, it became evident that our life savings and health insurance policies were not going to be enough to cover the expenses. After rehabilitation and therapy for several weeks, Rose was left partially paralyzed.

For months, I cared for her myself, keeping the house, dressing and bathing her, and then carrying her downstairs for the day. But I am 77 years old and I am not as strong as I used to be. Caring for Rose in our two-story house got to be too much of a strain for me.

The costs of the medical expenses and the strain of moving Rose around our house compelled me to sell our home. It was a sad occasion but we sold our home for \$37,000 in the spring of 1983. We moved to a small one-bedroom apartment in Rhawnhurst.

After the stroke, Rose was in and out of the hospital for ulcers, several minor strokes and cataract surgery. Each time she came home from the hospital, I had to try to take care of her. In 1985, I had lens implant surgery myself. And after the operation, the doctor said that I should not do any bending or lifting, nothing strenuous.

I decided to hire a home health aide to help me with Rose, because I knew that she wanted to stay at home. We hired a person to help around the house and a home health aide to bathe Rose and help her move around.

The costs of this care mounted quickly. Each time a person came in to help around the house for a minimum of three hours during the day, it cost me \$7 an hour -- at least \$21 a day. When the home health aide had to stay overnight during the weeks when I could not do anything for Rose, it cost \$70 a day for a five-day week, amounting to \$350 a week. I do not think I have to tell anyone what a strain that can be on people living on a fixed income.

On May 9, 1986, Rose was diagnosed with liver cancer. Our doctor told us she could live for up to five years but he could not be

sure. We were devastated but we decided the least we could do was to keep Rose comfortable. I did not want her to suffer.

Because her health did not improve and she was diagnosed as being terminally ill, Medicare coverage and all other insurance coverage stopped. I began paying \$2300 a month for the nursing home. In six months' time, I spent \$20,700 for her nursing home care.

To have to leave a loved one in a nursing home is emotionally and financially devastating. The families of the terminally ill face overwhelming financial burdens inflicted by these illnesses. Besides paying for the nursing home, I had to pay my rent, and had to pay for food, gas and electricity each month.

I have little left from the money that we gained from the sale of our home. I am 77 years old. If something should happen to me, I do not know what I would do. I do not want to be a burden to my family.

Diana Loshuk, daughter
Niles, Ohio

My name is Diana Loshuk and I am from Niles, Ohio. That's not far from Cleveland. My 65 year-old mother, Mrs. Dorothy Peters, has ALS or Lou Gehrig's disease and, because of that, I feel well-qualified to talk to you about what a truly catastrophic illness can do.

In a little over 4 1/2 years, my mother has been left a total quadriplegic and she's unable to speak. She requires constant care and attention. She has been a widow since 1984. She has been forced to sell her home, cars, and other personal assets to pay for her home health care because her private health insurance, Medicare and Medicaid, provide little, if any, assistance to people whose care they say is custodial.

Six weeks prior to Dad's death, Mom was diagnosed as having terminal ALS. She moved in with me and my two children and spent weekends with my brother and his family. Sometimes she went to stay with her sister in Pennsylvania. But soon the visits became too difficult and Mom's care was just too much for us to handle alone. So, we began to hire outside help to take care of her while I worked. We fixed up a large room in my house like a little apartment and furnished it with my mother's things from the home that she shared with Daddy for over 30 years -- the home she had to sell to help pay for the cost of her home health care.

As the disease progressed, Mom required more time and attention. For the past 3 years, she has had to have nursing care for 24 hours a day, 7 days a week. The cost of this constant care plus the needed medical equipment has been devastating. It took very little time to go through my parents' life savings of \$15,000. By Christmas of 1986, the cost of her care had also exhausted the \$55,000 she received from the sale of her home and other possessions. Now her only source of income is \$610-a-month from Social Security and my father's pension. This covers just over one-fourth the cost of the care that she needs.

Now I am trying to help pay for her care myself. It is very challenging -- emotionally, physically, and financially, but I care deeply about my mother, and I'm willing to do whatever's necessary to keep her at home.

Still, if nothing is done to help us, Mom will soon have to be placed in a nursing home. For her, this will be the equivalent of a death sentence. Even in the best of nursing homes, they are unable to provide the continuous, loving attention that an ALS patient needs. They don't have the staff, the time or the will. They will be forced to hook my mother up to all kinds of machines so that she can be monitored from a nurses' station. My mother's personal care in a home environment is, in my opinion, the single reason that she's still alive.

The other day, I asked my 8 year-old daughter, "How would you like to be poor?" She said to me, "How poor, Mommy?" I didn't want to paint too bleak a picture and tell her that we might lose our home, but that thought has entered my mind a few times.

The current American health care structure is tearing families apart. My greatest fear is that my mother's illness will not only destroy her, which is tragic enough, but may leave half a dozen other lives destroyed in its wake.

Senator SIMON. I thank you. You have brought up the unpleasant subject of how we are going to pay for it. You, in general, you talked about principles. One of the things that has been suggested as a way of paying for it, and it is expensive and let me just add, as strongly as I have been advocating this kind of a program, I am not going to advocate if it adds to the deficit. We simply have to stop borrowing from our children and our grandchildren. One of the proposals has been to lift the ceiling of \$45,000 on Social Security. We pay on Social Security up through the first \$45,000 we earn. We do not pay above that.

In order to not be an imposition on people of limited income, one of the suggestions has been that we take the lid off of Social Security and then add 1 percent on Social Security for money earned after the first \$15,000. Does that strike you as meeting the standards that you are talking about—if I can ask you to be a little more specific?

Ms. SCHAKOWSKY. Yes. We supported the financing mechanism, for example, in the Pepper Bill, the one that would have in fact lifted the cap on income exposed to the Social Security Tax or that portion that goes to Medicare. I think it is important to note that these costs are now being born, it is not like nobody is paying for long-term care. People are paying for it with a financial integrity of their families, with the devastation that it brings. And so, we feel that raising—that eliminating the cap on income, and I am sure all those people here that earn \$250,000 or more would be willing. Can we see hands of those people? There is a fellow over there. He is willing to pay a small portion of his income to know that his family and others will be able to guarantee it. That is the kind of mechanism we are talking about.

Senator SIMON. Let me just add. We are talking about something that is very expensive. If you say for those earning over \$100,000 a year, 1 percent in added income tax brings in \$2 billion a year, so it may be a combination of several of these things that will have to be done. But unfortunately, along with the need we are going to have to find a way for paying it. But if all the other industrial nations on the face of the earth can find a way of paying for it, the United States of America ought to be able to do that too. (Applause)

Ms. March, we are very happy to have you here with us and we thank you very much for being here.

Ms. MARCH. Thank you. Good morning, Senator Simon. I am Connie March and Vice President of Geriatric Services for Servant-Cor which is a health care system based in Kankakee, IL, and we do provide both acute and long-term care services to the citizens of Illinois.

I am here today representing Catholic Health Association, CHA, which represents over 600 hospitals and more than 251 long-term care facilities in the United States. CHA, whose Long Term Care Continuing Care Services Committee I chair, commends you, Senator Simon, for your unwavering commitment to the health and welfare of the nation's sick and infirm of all ages.

In the State of Illinois more than 6,100 beds are licensed beds that operate under Catholic auspices providing pediatric and adult, skilled and intermediate nursing care, as well as personal care,

adult day care, home health care, congregate housing, and a full complement of professional and rehabilitation services. Of the nation's one and a half million nursing home residents, only 3 percent have their stays paid for by Medicare. As you know, Medicare pays only for highly skilled nursing care. Therefore, Medicaid becomes the primary payor source for most of the people in the State of Illinois. But Illinois with its reimbursement rate of \$35.87, and that is an average rate, has one of the nation's lowest or worst Medicaid reimbursement rates. No single issue in long-term care deserves more attention or is more fundamental than the Medicaid reimbursement rate.

With few exceptions, Catholic sponsors and local boards have determined that the level of reimbursement is insufficient to provide the quality of care, and the dignity that their mission calls them to provide. Most Catholic sponsored facilities, therefore, subsidize 10 to 40 percent of the cost of care of residents receiving Medicaid funding. Low Medicaid rates cause a perverse chain reaction: inadequate reimbursement leads facilities to raise private pay rate which in turn speeds up the rate of impoverishment and qualification of Medicaid coverage. Providing quality care to long-term care residents for \$1.49 per hour is not a reasonable expectation.

In recent years, many Catholic health care organizations and systems have been expanding their long-term care and continuing care services. Catholic health care facilities have been asked to participate in the leadership of developing continuum of care, and to participate if a continuum of care is available in the town in which they are represented. A clear emphasis on client-focused care and community service can build a valuable community, and therefore, political support for the health care organization in an era of budget-driven public program cost reductions.

The current predominance of nursing care facilities as opposed to community services and the provision of long-term care is the direct result of what Medicaid will, and will not, pay for. The discontinuities in our present system of long-term care are marked by large gaps.

Viewed from a client oriented perspective, long-term care should assist the client, as he or she changes from one functional state to another, and should insure that the client receives the mix of formal and informal services needed.

In summary, Catholic health care organizations recognize the need to change the focus of health care delivery from an acute disease, episodic basis, to an array of multilevel services that is responsive to the client needs.

Senator Simon, the Catholic Health Association thanks you for your leadership in this area and pledges to work with you in development of long-term care policy for the elderly and infirm of this nation. Thank you

[The prepared statement of Ms. March follows:]

PREPARED STATEMENT OF CONNIE MARCH

Good morning, Senator Simon. I am Connie March, Vice President of Geriatric Services for ServantCor of Kankakee, Illinois, a healthcare system offering acute care and nursing care services to the citizens of Illinois and adjacent areas of the midwest. Today, I am speaking on behalf of the Catholic Health Association (CHA), representing over 600 member hospitals and more than 250 long term care facilities in the U.S. CHA, whose Long Term/Continuing Care Services Committee I chair, commends you for your unwavering commitment to the health and welfare of the nation's sick and infirm of all ages. We also applaud your efforts in the long term care arena, where you have been a concerned leader in addressing the true needs of the aging population.

The demographics of older America are by now familiar: the number of persons aged 65 and over is expected to swell from 29 million today to more than 34 million in the year 2000, and to more than 65 million by the year 2050. The most significant change in the U.S. population, however, is in the old-old population. The percentage of the very elderly, i.e., persons aged 85 or more, is rising sharply and will continue doing so into the indefinite future. Continued accumulation of the very old will have an impact on requirements for health and social services and government responsibilities, as persons outlive their social, familial, and financial resources.

In the state of Illinois, approximately 30 long term care facilities operate under Catholic auspices, providing adult and pediatric skilled and intermediate nursing care as well as personal care, adult day care, home health care, congregate housing, and a full complement of professional and rehabilitative services. Many of these services are accessible to the outside community as well as to the facilities' residents. Catholic long term care facilities provide more than 3260 licensed beds in Illinois, including both hospital-based and freestanding facilities. Additionally, Catholic facilities offer many community services for non-residents: assessment, case management, home care, family education and training, home-delivered meals, information and referral, home-based hospice, respite care and social services.

Of the nation's 1.5 million nursing home residents, only 3% have their stays covered by Medicare. Medicare requires that patients be capable of rehabilitation and covers only those who need highly skilled care. While the recent Catastrophic health insurance law strengthens a few long term care provisions of the Medicare program, Medicare remains designed essentially to assist only acutely ill patients. Part of the artificial distinction in the continuum of care was eliminated by Congress when it dropped the requirement that patients must be in a hospital at least three consecutive days before being admitted to a skilled nursing facility. The number of covered days of skilled nursing care was increased from 100 to 150 per year. Effective January 1990, home health services for patients are expanded to a maximum of 38

consecutive days of daily care if the restrictive previous eligibility requirements are met. In a significant loosening of previous Medicaid eligibility, the bill allows individuals with spouses in nursing homes to maintain a higher minimum level of income and resources while still qualifying for Medicaid coverage of long term care expenses.

Medicaid, therefore, is the primary source of payment for long term care services. But Illinois, with an average of \$35.87 per patient day (Illinois Dept. of Public Aid, FY87), has one of the nation's lowest Medicaid reimbursement rates. Medicare accounts for only a small fraction of total nursing home payments. Only four of Illinois' Catholic facilities reported any admissions where long term care insurance was a primary payor. Certainly, no single issue in the current long term care debate is more fundamental than the Medicaid reimbursement rate. States tend to reimburse facilities at the level necessary for facilities to meet minimum standards for state licensure. With few exceptions, Catholic sponsors and local boards have determined that the level of reimbursement is insufficient to provide the quality of care and personal dignity that their mission calls them to provide. Most Catholic-sponsored facilities subsidize 10 to 40 percent of the cost of care for a resident receiving Medicaid funding. Without additional reimbursement, nursing homes cannot provide the necessary quality of patient care. Priority should be given to paying more just wages to the givers of care and, in particular,

nursing staffs; therefore, improved reimbursement should be structured to pass through nursing salaries.

Low Medicaid rates cause a perverse chain reaction: inadequate reimbursement leads facilities to raise private pay rates which, in turn, speeds up the rate of impoverishment and qualification for Medicaid coverage. Five years ago, 25% of residents in Illinois Catholic long term care facilities were on Medicaid. Now, due not to new admissions but to residents who received quality care and ultimately outlived the private resources, the figure is 45%. Providing quality care to long term care residents for \$1.49 per hour is not even a reasonable expectation.

Illinois has had to deal with several recent hardships in long term care. Financial difficulties in the state during mid-1988 caused a reimbursement delay to long term care facilities of 2 to 3 months. Some facilities were at risk of closing due to the prolonged postponement of such a substantial portion of their income. This must not be permitted to occur again. Exacerbating the issue is the burdensome amount of paperwork and staff time required to comply with Illinois' regulatory requirements. As a result, scarce resources sometimes go to paperwork rather than needed patient care. The combination of being under-reimbursed and administratively over-regulated is resulting in an Illinois long term care system in distress.

Although many elderly citizens enjoy improved economic status, in part due to Social Security payments and Medicare

benefits, a disturbingly high percentage of them are poor. In 1985, 26 percent of men and 56 percent of women over aged 65 had incomes below \$7000. Poor persons already on public aid have few choices for quality care because of limited access to long term care services. The social support system for persons needing long term care comprises informal help from family and neighbors and formal services from public, private or voluntary organizations. Whatever services are provided for the frail elderly and whatever their mode of organization, the goal should be to recognize and reinforce, not replace, the informal care and support currently provided by family and neighbors. A proper balance needs to be maintained between the two forms of care. Unfortunately, the U.S. long term care system does not do an especially good job of maintaining this balance or of generally meeting the needs of persons needing long term care. The current predominance of nursing care facilities as opposed to community services in the provision of long term care services is the direct result of what Medicaid will or will not pay for. Home care derives much of its character from Medicare requirements designed for convalescence and rehabilitation following acute care.

In an ideal system of long term care, services should be client-focused and planning for them should be the combined task of the patient, healthcare professionals, community agencies, and the patient's familial support group. The discontinuities in our present system of long term care are marked by many large gaps: between institutional and community-based long term care, between

acute care and long term care, and between health and social services. Viewed from a client-oriented perspective, long term care should assist the patient as he or she moves from one functional state to another. Its primary objective must be to ensure that the client receives the mix of formal and informal services appropriate to his or her needs.

In recent years, many Catholic healthcare organizations and systems have been expanding their long term and continuing care services by adding intermediate and skilled nursing care services, adult day care programs, home health services, retirement housing, and a variety of other services. Catholic healthcare organizations are attempting to ameliorate the harsher aspects of the current long term care system by making it work better. Properly implemented, a continuum of care will better identify the frail elderly's needs and make available a wider spectrum of services than otherwise would be available. Catholic healthcare facilities are challenged to consider providing the leadership necessary to organize a continuum of care in communities in which one does not presently exist, and actively participate in the continuum of care where one is being planned or already exists. A clear emphasis on client-focused care and community service can build valuable community, and therefore, political support for the healthcare organization in an era of budget-driven public program cost reductions.

In summary, Catholic healthcare organizations are prepared to recognize the need to change the focus of healthcare delivery

from an episodic, acute-disease crisis orientation to a multilevel, integrated array of services that is responsive to patient needs and emphasizes prevention and rehabilitation. In its book A TIME TO BE OLD, A TIME TO FLOURISH: The Special Needs of the Elderly-At-Risk, the Catholic Health Association makes challenging recommendations for the Catholic Church, Catholic healthcare providers and government to shape a long term care system that is responsive to the elderly-at-risk and their caregivers' needs. Among the major recommendations it advocates are an increase in the Medicaid reimbursement rate, the development of a continuum of care premised on the needs of persons and communities rather than of budget-driven reimbursement mechanisms, and advocacy by healthcare providers of a more rational long term care delivery system.

Senator Simon, The Catholic Health Association thanks you for your leadership in long term care initiatives. CHA pledges to work with you and your staff in the development of a coherent long term care policy for the nation's elderly and infirm.

Senator SIMON. I thank you very, very much. You mentioned Medicaid. What happens is for most people when they have to take advantage of nursing home care, it doesn't take very long and you are wiped out. And that is true for almost all of us. I have a friend who was a bank president in a southern Illinois community, very proud—a leader in his community. They had saved. He ended up with some medical problems. Ended up in a nursing home. His savings were wiped out; his wife's savings. His wife today is on welfare. If you had told him 20 years ago his wife, his widow, would end up on welfare he just would not have believed that was possible. There is a special problem with Medicaid I will add, in Illinois and in some other States, with the rate of payment. I am introducing legislation, it may have been introduced the other day. If not already introduced, it will be introduced the first part of next week which would require States to pay within 30 days of acquiring a bill. That is somewhat technical, but believe me—necessary if we are to improve the quality of nursing home care.

One other point that you mentioned that is extremely important and that is Medicare. One of the things that happened back some years ago was we took, and it should never have happened but it was done to make the cost of the Vietnam War look not so great, we took the Social Security Trust Funds and made them part of the Federal budget. [For the record, there is a moaning from the audience.]

It was a great mistake. And it means that as we look to ways to address long-term care—it means two things. One is we fool ourselves on what the budget deficit is because the Social Security Retirement Funds, for example, are temporarily running a surplus of about \$39 billion. I am on the Budget Committee. I have to deal with these things. But it means a second thing. You try and balance the budget by effecting Social Security Trust Programs. And one of the areas that has received less attention than others is Medicare. The requests right now is to reduce Medicare funding from its anticipated growth by \$5 billion.

Now, three things occur when that happens. One is, and some of you over 65 here have experienced this, you are paying a higher and higher percentage of the health related costs. Number two, we are having a lot of hospitals that are closing. St. Anne's, not too far from where we are having this hearing, is an example right here in Chicago. We have had 32 hospitals close in Illinois in the last eight years, and that is largely because of Medicare and Medicaid problems. And a third thing that is happening that most people aren't aware of and that is, in the previous panel one of the members of the panel talked about insurance premiums going up. When the Federal Government doesn't pay its obligation on Medicare and Medicaid that is shifted over then to the nonMedicare, nonMedicaid, patient and to insurance bills. And so our insurance premiums are going up.

But I appreciate your testimony, Ms. March, and what you have said is some of the nuts and bolts of delivering health care. It may not be very exciting in terms of reading or listening to, but it is really very, very vital. And I thank all three of you for your testimony. We are grateful to you. (Applause)

And our final panel is made up of Mr. Robert J. Sell, Ms. Anne Katterhagen, Ms. Wendy Meltzer, and Mr. Edward Truschke.

And let me just mention while they are coming up. We received additional written testimony from June Panatowsky for Alzheimer care at home and in nursing homes. We have also had a letter submitted by Mary Lou and Seigel Klein of Glen Elyn, IL. Mary Lou has multiple sclerosis, and both Mary Lou and Seigel Klein are present and we thank you for being here.

After this panel is finished, we are going to have I think probably, 20 minutes or so for questions or comments from the audience. And if the previous panelists don't mind coming up here and taking their place up in front here, we can have questions from the audience to anyone on the panels.

First let me call on Bob Sell who is a member of the National Legislative Council of the AARP. I am very happy to have you here with us, Mr. Sell.

STATEMENTS OF ROBERT J. SELL, ANN KATTERHAGEN, WENDY MELTZER, AND EDWARD F. TRUSCHKE, A PANEL ON CARE DELIVERY SYSTEMS

Mr. SELL. Thank you very much, Senator, and good morning. Before I start, I want to commend you for conducting this hearing on this very serious family problem of long-term care.

This morning because of time limitations I will be talking with you about just one aspect of it, the need for a social insurance approach to long-term care.

In my written testimony I have addressed AARP's position on other aspects of the problem, including sources of revenue which the Association believes are appropriate from financing a long-term care program. AARP believes there is a need to provide universal protection against the catastrophic cost of long-term care based on the insurance principle of shared risk.

At any one point in time, a relatively small proportion of our population will face catastrophic long-term care expenses. Although it is nearly impossible to predict just who those individuals will be, 1 out of every 4 individuals over the age of 65 will be admitted to a nursing home in the course of his or her lifetime. These facts argue inherently for an insurance approach to the problem. The costs to any one person will be small while offering protection to all against catastrophic expenses. Currently, society is bearing the cost, but in a very uneven manner which places an unfair burden on the victims of chronic illness and their families. These costs must be spread across the entire population in a more affordable, equitable manner. The broader the risk is shared, the lower the cost will be for each individual.

Responsibility for long-term care insurance must also be shared between the public and the private sectors of our economy. AARP encourages the development of private sector approaches, as at least partial solutions to the problem of financing a long-term care system the nation needs. long-term care coverage, for example, should be offered as an optional benefit under group health plans.

We do not believe, however, that an exclusive or even a predominant reliance upon private sector approaches is likely to be a

viable solution to the long-term care financing problem. Recent research by the Brookings Institution indicate that private approaches would lead to only a small reduction in total long-term care expenditures, and the numbers of persons "spending down" onto Medicaid.

The Association believes that universal insurance coverage is needed to solve the problems of catastrophic long-term care expenses, and that additional funds will be needed. Government expenditures will need to rise. If spread across people's working lives, comprehensive long-term care coverage is certainly affordable.

Our Nation has a long and successful tradition of providing protection through social insurance against the risks that threaten the basic security of Americans, such as that provided by Medicare and Social Security. The time has come to extend this same kind of protection to all persons, of all ages, with chronic long-term care needs.

Thank you very much, Senator.

[The prepared statement of Mr. Sell follows:]

PREPARED STATEMENT OF ROBERT J. SELL

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be spread across the entire population in a more affordable, equitable manner. The broader the risk is shared, the lower the cost will be for each individual.

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Our nation has a long and successful tradition of providing protection through social insurance against risks that threaten the basic security of Americans, such as that provided by Medicare and Social Security. The time has come to extend this same kind of protection to those with chronic, long-term care needs.

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NEED TO EXPAND NURSING HOME COVERAGE

Nursing Home Stays account for over 80 percent of the expenses incurred by older people who experience very high out-of-pocket costs for health care, defined those over \$20,000 per year. Indeed, the amount older persons paid out-of-pocket for nursing home care in 1986 exceeded the amount they paid out-of-pocket that year for all hospital inpatient care, physical services, and drugs combined. Clearly, this is because the annual cost of a nursing home stay is about \$25,000.

The need for long-term care leads almost inevitably to an unmanageable financial burden because the costs of care -- be it at an institution or in the home -- are often enormous. Medicare and private insurance combined pay less than 3 percent of nursing home costs. More than half of nursing home costs are paid out of the pockets of residents or their families. Most of the remaining costs are paid under Medicaid.

It is not generally recognized that the proportion of total nursing home costs being paid out-of-pocket has risen substantially in the last decade, i.e., from 42.7 percent in 1975 to 51.4 percent in 1985 - an increase of about 20 percent. At the same time, the proportion of nursing home costs funded by Medicaid and Medicare has been decreasing. In absolute terms, the amount Americans were paying out-of-pocket for nursing home care rose from \$4.3 billion in 1975 - to \$18.1 billion in 1985, - an increase of 420 percent. Even when this is corrected for inflation, out-of-pocket spending still more than doubled.

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Few people can afford the expense of an extended nursing home stay, so many eventually end up on Medicaid, but only after financial catastrophe has occurred. Almost one-half of Medicaid dollars for nursing home care is spent on behalf of persons who enter nursing homes as private paying residents. The process of "spending-down" one's income and depleting one's assets to qualify for Medicaid can occur very quickly. A 1985 study conducted for the House Aging Committee found that approximately two-thirds of single, older persons and one-third of couples in Massachusetts were impoverished after only 13 weeks in a nursing home.

Our public policies should not force older Americans to exhaust their life savings in order to receive needed long-term care services. America can do better. We need to provide our citizens with real protection against the crushing costs of a nursing home stay.

NEED TO EXPAND HOME AND COMMUNITY-BASED CARE

Given the strong preference of older people to remain in their own homes, the lack of access to community-based services is the most pressing gap in the current long-term care system. Poll after poll have confirmed this strong preference. Compared to expenditures for institutional care, expenditures for community-based services are minute. This clearly demonstrates that the Medicare and Medicaid programs have a strong institutional bias. Medicare's expenditures for home health services, which largely are limited to skilled nursing and rehabilitative care, represented only 3.4 percent of the Medicare budget in 1986.

Without question, the Medicare program needs to be expanded to cover more 'al and personal care needs for the functionally dependent.

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Expenditures for community-based services under Medicaid are similarly limited. Less than two percent of Federal-State Medicaid expenditures are for Home Health Services. In addition, the numbers served under the Medicaid Home and Community-based 2176 Waiver Program, which allows states to provide a range of community services, have remained very small.

While home care, including homemaker and personal care services, is a service category under Title III of the Older Americans Act, the low level of resources allocated to the program severely restrict its impact. Similarly, the social services block grant program under Title XX, which primarily serves low income, provides a variety of social services to a diverse population but faces many competing demands. Its support to the long-term care population is very limited.

The time has come to acknowledge that expanding community-based long-term care services is necessary, even though overall costs could increase as a result of additional demand. Most studies, however, including the experience in Canada, indicate that better coverage will not result in people coming out of the woodwork and overutilizing these benefits. People do not relish the thought of bringing strangers into their homes, particularly when the safety of vulnerable, dependent older citizens is at issue. There are powerful reasons for expanding such services: they often result in better care, they fulfill unmet needs, and they are desired by American citizens. They will also help to keep families together, something in which our current "non-system" is failing horribly. For many persons, particularly those under the age of 65, community-based services are often much less expensive than care provided in an institutional setting. Over the long run, expansion of community-based long-term care services will result in a more balanced, efficient system of providing long-term care.

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LIMITS OF PRIVATE INSURANCE

Although the private long-term care insurance market will provide a great diversity of products to a larger number of people, we should not harbor unrealistic expectations about its potential. Many uncertainties and problems remain which cast doubts on the ability of the private market to provide adequate protection against the risk of needing long-term care coverage.

For example, Sufficient data to accurately predict future use and costs of long-term care services are not yet available, especially for home care services. The nature of this risk and how to manage it also are not well understood. Less is known about chronic disability than about acute care, and insurers have not yet been able to precisely define what is being insured.

These uncertainties and problems cause insurers to place significant limitations on the risks they are taking and the coverage they offer. These restrictions and exclusions limit the product's effectiveness. Plans are generally not indexed for inflation and hence will fail to keep up with the escalating costs of care. Many plans also require a substantial deductible. The many policies which still require prior hospitalization before covering a nursing home stay can effectively deny coverage to Alzheimer's patients and others whose need for long-term care services may not begin with an acute care episode. Non-skilled home care is infrequently covered, or a nursing home stay may be required in order to trigger home health benefits.

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Perhaps most important, current long-term care insurance policies are inaccessible to many older persons due to cost and underwriting restrictions. For most policies, the premium is determined by the age of the insured when he or she first buys the coverage. The monthly premium for a sixty-six year old is generally over \$50; and for a seventy-six year old over \$100. Few insurers will even sell to those over eighty years of age.

The Brookings Institution Report indicates that a substantial proportion of the elderly might not be able to afford private insurance coverage and that the private sector cannot become the dominant form of long-term care financing.

Additionally, even many people who could afford private insurance might not be able to purchase it because those with pre-existing conditions, such as Alzheimer's Disease, are not eligible for most insurance plans.

Finally, private long-term care insurance also faces major demand problems for a variety of reasons, because people underestimate or deny their future long-term care needs.

For all these reasons, it is clear that private insurance cannot solve our nation's long-term care crisis by itself, and that a new, comprehensive federal program is needed.

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REVENUE OPTIONS

Today, society - in one way or another - pays most of the costs of long-term care. But it does so by placing inordinate burdens on a few individuals and their families, often robbing the family of dignity and independence in the process.

Addressing this concern will require a plan that is both economically and politically feasible. The Association is committed to developing a long-term care proposal which does not increase the deficit. It will also be important to spread the risk of the extraordinary cost of long-term care across the broadest possible population.

Perhaps the best way to begin to think about creating a financing mechanism for a comprehensive long-term care program is through a two-tiered structure: one part designed on classic principles of a pre-funded social insurance system, and a second part designed to address the needs of those currently using long-term care services or who will soon need them.

To protect younger persons, a standard social insurance approach seems most feasible. Through an increased payroll or income tax, a fully funded system could be established that would offer future generations protection from the catastrophic impact of a long-term illness or disability.

However, to launch a long-term care program and to begin to provide benefits to those who would be eligible in the first years of a program, a package of revenue sources seems most feasible.

The Association views several financing sources as appropriate for financing the early years of a program.

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EXTENDING THE HEALTH INSURANCE (HI) PAYROLL TAX TO ALL STATE AND LOCAL EMPLOYEES

About 75% of these employees typically become fully eligible for Medicare benefits through subsequent non-government employment or through a spouse. Requiring participation on their part would eliminate this inequity and, at the same time, raise necessary revenues for the first decade of the program.

UNCAPPING THE HOSPITAL INSURANCE (HI) PAYROLL TAX

Subjecting all wages to the 1.45% HI is viewed by the Association as a logical health care financing source. It would have the added advantage of making the HI TAX burden more equal among all incomes.

INCREASING THE ESTATE AND GIFTS TAX

Increased taxation of assets at death provides an alternative to the denial of coverage under a long-term care system for those whose assets exceed arbitrary amounts.

INCREASE THE EXCISE TAXES ON ALCOHOL AND TOBACCO

While excise taxes are looked to as a revenue source for almost every program, we do know that smoking, in particular, has a great impact on an individual's need for health care.

IN CONCLUSION:

The Association looks forward to working with congress to find realistic solutions to the long-term care financing problem. We believe Americans are ready to face this challenge to protect current and future generations of families from the devastating costs of illnesses that require long-term care.

Senator SIMON. I thank you very, very much. And I think the key to all of this is three or four words you used, and that is, the burden is uneven. There is no reason that some families should just get overwhelmed with problems while others of us pay nothing at all and do nothing to share in that burden. Somehow all of us ought to be able to share in that burden.

And forgive me, Ms. Katterhagen, and she is a leader nationally in this field.

Ms. KATTERHAGEN. My name is Anne Katterhagen. I currently am Vice President of Memorial Medical Center. I am President of its affiliated company responsible for in-home services in Springfield, Illinois. The services I am responsible for are those such as the Visiting Nurse Association, Hospice Care of Central Illinois, and Memorial Home Care. These three operations serve over 2,000 home health clients annually.

Also, I am currently Chairman of the National Association for Home Care called NAHC. NAHC is the largest professional organization representing the great majority of home health agencies, homemaker-home health aide services, and hospice organizations here in the United States. One of NAHC's goals is to assure the availability of quality, cost effective services to those who need them.

We very much appreciate the opportunity to testify before this committee to discuss with you the issues of long-term care. Currently, the majority of people served by our members are age 65 and older, and it is not at all unusual for the median age of clients served by an agency to be above 75 years old. The age at which functional disabilities become more and more common in daily lives. We applaud you, Mr. Chairman, on holding this hearing and for providing the leadership that you have, both in the 100th and 101st Congress, in addressing this extremely important issue of the need for provision of health and long-term care to our aging and disabled population.

We are an aging nation. We have been talking about this all morning. With the advent of new technology and the dramatic changes in treatment of previously fatal diseases, more and more of our fellow Americans are living into their 80's and 90's. Nationally there was a 63 percent in the Medicare enrollment between 1967 and 1986. This tremendous growth, however, doesn't take into effect the baby boom generation and its graying that we have coming.

I guess it is a good news, bad news, situation. The good news is that we are all living older, the bad news is it gives us a chance to develop more chronic illnesses, such as arthritis and lung diseases and cancer.

Our current Medicare system is not developed to deal with chronic disease. In fact, treatment for chronic conditions is not allowable under the home health benefit in Medicare. If you have Alzheimer's you are not allowed care because it is not an allowable diagnosis. Medicare writes it out.

As described in the written testimony that I have provided, Medicare requires a patient to be actively treated and making progress or their treatment is not considered to be medically necessary. Of course, this kind of nearsightedness is pennywise and dollar foolish

since it, in essence, encourages the development of more difficult systems and higher disease treatments. In my written testimony we have proposed a system of long-term care that would create a Federally funded benefit, thereby spreading the costs and allowing for comprehensive, consistent basic benefits.

A privately purchased supplemental policy could also be made available. Such benefit should be based on acute and chronic long-term care, plus back up coverage in nursing homes for those times or situations when care in the home cannot be safely and appropriately provided. Both systems should contain provisions for utilization review in case management techniques to be accomplished by both the payor and the provider of care. These two should be statistically valid assessment and evaluation tool. Admission to the long-term care program should be made through an assessment of functional needs, not medical diagnosis.

We believe integration of these current health care systems into the most cost effective program utilizing the home as the major focus is the only way to successfully meet the challenge.

In conclusion, we very much appreciate the opportunity to come to Chicago and to testify today on this vitally important issue. We again commend you, Senator, for your pro-active leadership in this area and hope to be able to work with you in the enactment of Long Term Care Bill in this 101st Congress. Thank you.

[The prepared statement of Ms. Katterhagen follows:]

PREPARED STATEMENT OF ANNE M. KATTERHAGEN

I. INTRODUCTION.

Mr. Chairman and Members of the Committee:

My name is Anne Katterhagen. I am Vice President of Memorial Medical Center and President of the affiliated company responsible for in-home services in Springfield, Illinois, such as Visiting Nurse Association of Central Illinois, Hospice Care of Illinois and Memorial Home Care. These corporations provide skilled, professional home health service, hospice service, high-tech infusion and oxygen therapy, and durable medical equipment to over 2,000 people in Central Illinois annually.

Also, I currently am the Chairman of the Board of the National Association for Home Care (NAHC). NAHC is the largest professional organization representing the great majority of home health agencies, homemaker-home health aide, and hospice organizations here in the United States. One of NAHC's goals is to assure the availability of quality, cost-effective home care services to people who need them.

We appreciate the opportunity to testify before the Committee to discuss with you the issues of long-term care. Currently the majority of people served by our members are age 65 and older, it's not at all unusual for the median age of the clients served by a home health agency to be above 75 years of age, the age at which functional disabilities become more common in their daily lives. We applaud you, Mr. Chairman, on holding this hearing and for providing leadership in the 100th and 101st Congress in addressing this extremely important issue of the need for the provision of health and long-term care need to our aging and disabled population.

We are an aging nation! With the advent of new technology and the dramatic changes in the treatment of previously fatal diseases, more and more of our fellow Americans are living into their 80s and 90s. But not without health problems!

After age 60, the chance of contracting a chronic illness increases dramatically! Diseases such as diabetes and its devastating complicating illnesses of blindness and heart disease; osteoporosis and its compressed fractures resulting in constant pain and inability to walk, arthritis, cancer and chronic lung problems to name just a few more. In 1986, the Government Accounting Office issued a report entitled, "Medicare: The need to strengthen Home Health Care Payment Controls and Address Unmet Needs" which stated that an estimated 3.2 million persons needed assistance to stay in their homes, of those, only 1.9 million were receiving help.

Today, we have waiting lines for admissions into long-term care facilities in some areas of the country, especially if you happen to need a higher level of care than the average skilled nursing facility patient or if you do not have private insurance. People who are dependent on a ventilator sometimes with paralysis, are having a very difficult time finding placement in a skilled nursing facility. Many times these people could be appropriately cared for in their homes but because the Medicare home health benefit eligibility requirements state that a patient must be "showing progress", that is the person must be getting better or sicker", people with chronic illnesses or conditions are not eligible for the benefit.

Let me give you some examples of what I am talking about.

Jane is a 69-year old lady with severe arthritis - so much so that she had to have both knee joints replaced. One of the joint replacements became infected during her hospital stay and ultimately the joint was removed in order to allow the osteomyelitis to heal. Remember, she has no knee joint in her leg, she wears a brace on the leg around the house to do her meal preparation, etc., and uses an ambulance for transportation to her physician. Unfortunately, visiting her doctor made her "not homebound". By being "not homebound", according to the government's definition, this poor lady was ineligible for Medicare home care.

For the approximately 50% of cancer patients that are not cured of their disease, the usual progress is one of increasing deterioration interspersed with periods of remission. These remissions can be characterized as a couple of days of symptom-free life to months or years of lack of disease progression. Of course, the length of the remission shortens as the cancer progresses and death approaches. The length of the remission is not predictable and in the later stages of the illness, most agencies reduce the number of visits to the patient while maintaining the assessment and evaluation visits knowing that in the vast majority of cases, symptoms will reoccur.

Such is the case of Bill who had had cancer of the prostate for four years but now it had metastasized to the bone and lung, causing increasing pain, difficulty ambulating and increasing difficulty breathing.

A World War II veteran, Bill has seen a lot of adversity and though a widower and alone, wants to remain home as long as he can with his pets and family treasures. Also, he has a small favorite garden outside the back door that he used to work in though now he only gets out during rare periods of remission.

Bill's problem in the Medicare system is not uncommon, as his disease becomes quiescent and goes into remission, he becomes ineligible for care under the government's definitions. And yet, in order to remain at home, he is still in need of homemaking service and regular evaluation to monitor the progression of the disease and identify the first signs of reoccurrence.

We have an overburdened non-system for the provision of long-term care service today - however, the need for these services in the future, will be even greater! Not only do we have the so called baby-boomers approaching mid-life, but the utilization of health care and other services by this generation is very different than other generations. If we consider the current long-term care user as over age 65, and look at their history, we can see they grew up prior to or during the depression. For the first 30 to 40 years of their lives, there was little or no health care - they learned to go without, perhaps most importantly in terms of today's use, they accept the premise that you only went to the doctor or hospital if you were really sick - meaning dying. That philosophy continues today.

Compare that with the current 30 and 40 year olds. This is the generation that was taught to be "sick successfully". This is the generation that went to doctors when they were well and sick - not just when they were dying. While this group is generally more healthy than past generations due to a variety of reasons such as better diets, they also know how to access and use the health care system.

I would suggest that we mustn't wait until this group turns gray to develop answers to this increasing problem, we must begin now. Otherwise, we will be overwhelmed by the need.

II. ACTION REQUIRED

We believe the only way to address this problem successfully and equitably is to develop a national long-term care program that is comprehensive in scope. Spreading the cost of a long-term care policy over the entire population will enable a basic range of services to be provided to all citizens. Additionally, a privately funded supplemental policy could provide for service over and above the basic range.

Further, we believe that the foundation for this new benefit should be home care. Prevention of exasperation of illness through the provision of what is characterized as acute home care can reduce reinstitutionalization in expensive acute care facilities.

Long-term home care will provide services to those individuals described in earlier testimony that need assistance in activities of daily living. When a patient's custodial or skilled needs become too great, the patient could then be placed in a nursing home, when constant long-term care is necessary.

Eligibility for long-term care service should be contingent on a functional assessment through a statistically valid functional assessment tool. People should not be required to be homebound or only need part-time or intermittent service since requirement would not assist in maintenance of the patient in the least costly area.

A long-term home health benefit would include skilled, professional services for regular evaluation assessment and treatment of the chronic condition. Respiratory therapy and nutrition services would be added benefits since these services are not currently available and yet are so integral to health.

Home health aide/homemaker services would be a key component of a long-term care benefit. Home health aides provide hands-on care - services frequently done by nurses in hospitals. These caregivers are extensively trained and work closely with nurses. This relationship and frequent communication between the aide and nurse provide for the early recognition of an exacerbation of illness or potential complication. Homemakers would provide respite care for the providers of care in order for them to be able to manage the stress of providing the care 365 days a year.

Additional services such as patient care education sessions and emergency response systems should be included.

A clear and definite distinction between the current Medicare benefit - the so-called acute home care benefit and a long-term home care benefit must be made. Discharge criteria for the current benefit must be established.

Utilization of the benefit should be controlled by use of valid, standardized, functional assessment tools and the use of case management techniques similar to those used in the social HMO demonstration projects. These two responsibilities could be divided between payors and providers of services to recognize the corresponding obligations. Through utilization management, the payor can protect the program against over-utilization and excessive costs. The responsibility for managing the care, services, and functioning as the patient advocate should remain with the providers who are trained in evaluation and assessment, see the patient on a regular basis, are the most knowledgeable about the needs of the patient, and also responsible to the patient.

A balance between these two functions must be achieved. The alternative is to develop duplicative, costly, bureaucratic structures to perform the functions.

Finally, but certainly not least, any system must provide adequate reimbursement related to services provided. For government to encourage, if not require cost shifting, as the current Medicaid home care payments in many states does, is nothing more than additional secret taxes on purchasers of health care.

III. CONCLUSION

We very much appreciate the opportunity to come to Chicago and testify today on this vitally important issue. We again commend you for your proactive leadership in this area and hope to be able to work with you in the enactment of a long-term care bill in the 101st Congress.

Thank you.

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Senator SIMON. I thank you. Let me just ask you. Mr. Sell has suggested a national insurance program. We heard Ms. Schakowsky earlier suggest something along the same line. Does that meet the kind of requirement you are talking about?

Ms. KATTERHAGEN. Certainly it does. We believe that would spread the cost and make access more available to those who need, instead of being inconsistent as it is today.

Senator SIMON. Thank you. Our next witness is Wendy Meltzer who is the staff attorney for Illinois Citizens for Better Care. Happy to have you with us, Ms. Meltzer.

Ms. MELTZER. Thank you. My name is Wendy Meltzer. I am staff attorney for Illinois Citizens for Better Care, the Illinois nursing home patients' advocacy group. We are nursing home residents and their families, and public health and other professionals concerned with nursing home issues.

I understand most of the witnesses are here today to emphasize the need for increased government funding for long-term care and long-term care alternatives. At ICBC, we certainly do see people forced to enter nursing homes because their families cannot afford to pay for the daily care they need at home, or to quit work to provide that care themselves. Those families are then brought to destitution or its brink, as the price of entering and remaining in a decent facility. It is also true that the amount the Medicaid program pays in Illinois for long-term care is not adequate to meet the needs of nursing home patients. It is also true, however, that we have seen nursing home patients whose families were paying up to \$5,000 a month for their care, who entered nursing homes merely because they are frail or slightly confused, or perhaps withdrawing from alcohol dependency, and within one or two months are dead because of such unremitting, unfeeling neglect that their relatives, even months later, cannot believe what they have themselves witnessed.

Money alone is not the answer to improving the quality of long-term care. Pay more for crummy care without intelligent regulation, and you get more expensive crummy care. Any increase in Medicaid funding, any broadening of Medicare long-term care eligibility criteria and resultant increase in Medicare funding, needs to be used intelligently, not to increase the profits of nursing home owners. At least the bulk of any increase should be required to be used to pay for additional nursing staff and aides, and to raise salaries for nursing staff and aides.

In addition, the government can take the following steps, none of which would cost a penny, to improve the quality of nursing home care:

1. Require all nursing homes to participate in the Medicaid program, and to accept a minimum fair share percentage of Medicaid patients.
2. Prohibit nursing homes from making political contributions to state political campaigns, and from employing state legislators and their law firms.
3. Prohibit state legislators from having a financial interest in nursing homes.
4. Require all nursing homes to cooperate in establishing family councils for each home, require nursing home administrators to

meet regularly with those councils, and offer potential new residents and their families the opportunity to meet with representatives of the family council before signing a contract or entering a home.

Thank you.

[The prepared statement of Ms Meltzer follows:]

PREPARED STATEMENT OF WENDY MELTZER

My name is Wendy Meltzer. I am staff attorney for Illinois Citizens for Better Care, the Illinois nursing home patients' advocacy group. We are nursing home residents and their families, and public health and other professionals concerned with nursing home issues.

I understand most of the witnesses are here today to emphasize the need for increased government funding for long term care and long term care alternatives. At ICBC, we certainly do see people forced to enter nursing homes because their families cannot afford to pay for the daily care they need at home, or to quit work to provide that care themselves. Those families are then brought to destitution, or its brink, as the price of entering and remaining in a decent facility. It is, also true that the amount the Medicaid program pays in Illinois for long-term care, is not adequate to meet the needs of nursing home patients. It is also true, however, that we have seen nursing home patients whose families were paying up to \$5000 a month for their care, who enter a nursing home merely because they are frail, or slightly confused, or withdrawing from alcohol dependency, and within 1 or 2 months are dead because of such unremitting, unfeeling neglect that their relatives, even months later, cannot believe what they have themselves witnessed.

Money alone is not the answer to improving the quality of long term care. Pay more for crummy care and you get more expensive crummy care. Any increase in Medicaid funding, any broadening of Medicare long term care eligibility criteria and resultant

increase in Medicare funding, needs to be used intelligently, not to increase the profits of nursing home owners. At least the bulk of any increase should be required to be used to pay for additional nursing staff and aides, and to raise salaries for nursing staff and aides.

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3. Prohibit state legislators from having a financial interest in nursing homes.
4. Require all nursing homes to cooperate in establishing family councils for each home, require nursing home administrators to meet regularly with those councils, and offer potential new residents and their families the opportunity to meet with representatives of the family council before signing a contract or entering a home.

Thank you.

Senator SIMON. I thank you. I thank you for your very forthright statement. And let me just, because you mentioned money alone, and you mentioned some specific steps that do not require money. Let me just add one word for whomever may be listening who has a relative in a nursing home. I visit nursing homes quite a bit and the one disease that is the worst of all, is the disease of loneliness that so many people face. If you have relatives, friends in a nursing home, even if you can't visit, just a postcard or a letter means an awful lot to people. There is no way the Federal Government or State Government or Local Government can require this. This is something we all just ought to be doing. I thank you very, very much for you statement.

And finally, Mr. Ed Truschke who is the President of the Alzheimer's Association. Very happy to have you here with us, Mr. Truschke.

Mr. TRUSCHKE. Thank you, Senator Simon. I represent the National Alzheimer's Association, an organization with 197 chapters in 48 states, around the country, with more than 30,000 volunteers working in a variety of program activities, including research, education, advocacy and patient and family services.

Alzheimer's is the most common form of dementia, a progressive irreversible disease which attacks the brain and strips away a person's mental and physical conditions. Typical symptoms include gradual memory loss, disorientation, impaired judgments, and in its final stages, loss of bodily function. It is the fourth leading cause of death, an estimated 7 to 9 percent of persons aged 65, and 25 percent of those over 85 have the disease, but it is not strictly limited to those age groups.

You have heard today from professional experts, and certainly panelist of caregivers, and certainly I want to add that Alzheimer's patients and their families have an important stake in long-term care. Seventy—80 percent of long-term care services are provided by informal caregivers, often families and friends. Sixty-three percent occur in residents in nursing homes experience cognitive impairments, primarily due to some form of dementia, with the average cost being \$25,000 a year.

Those are numbers and they are important numbers when you are making a case for policy and change, certainly, I think it is great that we are able to bring that to this audience and to the Senator. What we have also heard today, and the testimony is certainly eloquent, and Mr. Jim Spiro and other caregivers here, is the human dementia and cost of these diseases, and therefore, the importance of establishing a long-term care policy in this country.

The Alzheimer's Association supports the establishment of a universal comprehensive long-term care program. Its coverage should be available to all persons who need community or facility based long-term care services, regardless of age, income, marital status or availability of informal supports. Eligibility determination should go beyond traditional measures of disability to include functional, cognitive, or behavioral limitations, including the need for supervision or the need for verbal reminding or cueing and should be flexible to accommodate individual situations.

The entire range of home and facility based services should be offered with an emphasis on enhancement of personal independ-

ence in a setting preferred by the beneficiary and the family. Family should have a key role in decision making, if members are available. Education and training for providers and informal caregivers is needed. A public long-term care program should be supported through sources of financing which are progressive. It should be based on the traditional social insurance concept where financial risk is spread as widely as possible. Protection from out of pocket costs for low and moderate income persons should be provided. Cost containment measures should be built into the program, while quality assurance controls are incorporated.

The Alzheimer's Association is proud to become one of the lead partners of the National Long Term Care campaign, in recognition that we are one of the many groups concerned about this critical issue.

Senator Simon, at the Alzheimer's Association we have a byline that says, "We are there to stand by you." And may I take this opportunity on behalf of 2 1/2 to 3 million victims and the 7 to 8 million caregivers who are representative of our Association to say to you, thank you for standing by us in highlighting and maintaining this important dialogue on the long-term care issues at these hearings.

Thank you very much.

[The prepared statement of Mr. Truschke follows:]

TESTIMONY FOR SENATE LABOR AND HUMAN RESOURCES COMMITTEE
FIELD HEARING, CHICAGO, ILLINOIS, MARCH 13, 1989

EDWARD F. TRUSCHKE, PRESIDENT OF ALZHEIMERS ASSOCIATION

I am Edward F. Truschke of Chicago, Illinois, President of the Alzheimer's Association, the leading national organization representing over four million Alzheimer's and related disorders patients and their families and caregivers. The Association, founded in 1980, currently has 197 chapters in 48 states, sponsors over 1500 support groups and has more than 30,000 volunteers working in organizational activities. Our volunteers include family members, caregivers, scientists, health and social services professionals and other concerned citizens.

Alzheimers Disease is the most common form of dementia, a progressive irreversible disease that attacks the brain and gradually strips away a person's mental and physical capacities. Typical symptoms include gradual memory loss, disorientation, impaired judgment, and in its final stages loss of control of bodily functions. The course of the disease normally runs from three to more than twenty years. Alzheimers is the fourth leading cause of death. The cause of the disease has not been determined.

Alzheimers Disease afflicts individuals of every social and

economic strata. An estimated 7 to 9 percent of persons over age 65 (25% of those individuals over age 85) have the disease, but it is not exclusively a disease of the old. 15% of persons over the age of 65 have a mild, moderate or severe form of Alzheimers or a related disorder.* As more and more people live to an older age, the incidence of Alzheimers Disease will rise dramatically; a five-fold increase is expected by the year 2040. At least 25% of Americans now in their 20's and 30's will develop Alzheimers Disease before they die, unless we find a cure. The total economic cost to society, now estimated to be over \$80 billion annually**, also will increase in proportion to the number of people afflicted.

The Alzheimers Association has five major goals reflected in its mission statement:

1. Supporting research into the cause, treatment, cure and prevention of Alzheimers Disease and related disorders.
2. Stimulating education and awareness of the disease among the general public and professionals.
3. Establishing the formation of a nationwide family support network of chapters and support groups.
4. Advocating for public policies that address the needs of patients and their families and caregivers.
5. Enhancing the quality, availability, access to and appropriateness of services for patients and caregivers.

The Alzheimers Association is pleased to testify at this important hearing on long term care because long term care is a number one priority for our patients and caregivers.

Alzheimers and related disorders patients constitute nearly two-thirds of the nursing home population and perhaps one-third to one-half of the home-based long term care population. Approximately 70 to 80% of long term care services are provided by informal caregivers at home, often families and friends. The lack of available, affordable services is a particular problem for our patients and their families, individuals who are placed under tremendous stress because of the progressive nature of the disease, its often long duration and the difficulties of caring for dementia patients.

Caregivers are often faced with pitting the care needs of the Alzheimers patient against the other demands made upon them by other members of their family, their employers and the general community. In the early stages of the disease outsiders may not be aware of the severity of the patients condition: the person may look as though they are "fine" since, usually, no physical symptoms are exhibited.

Meanwhile, even during these early stages family caregivers are tormented by the reality that their ill relative is not functioning normally and that their minds, abilities and personalities are disintegrating. Even in the early stages patients may need constant supervision in order to protect

themselves and others from danger. As the disease progresses, patients lose more and more cognitive abilities and may develop a variety of inappropriate behaviors which compound the difficulties of caring for them. Eventually patients lose the ability to understand, recognize people, talk, walk and take care of basic bodily functions. At some point in the disease family caregivers may find they can no longer care for the patient at home and face the difficult decision of institutionalizing the patient. For the vast majority of families, this is the last, exceedingly painful, resort and many families continue to be actively involved in the care of the patient while they are in the nursing home. One should also note that studies have shown that many Alzheimer patients do not have families and that as many as 25% of even severely demented patients are living alone at great risk to the safety of themselves and others.

63% of the current residents of nursing homes, or 940,000 persons in 1985, experience cognitive impairment primarily due to having some form of dementia.*** The average annual cost of nursing home care in 1985 was \$25,000, an amount which rapidly exhausts the resources of all but the most wealthy. The current Medicaid program requires patients and their spouses to impoverish themselves before they are eligible for assistance and in effect encourages the dissolution of families.

Currently the nation's health care system is poorly equipped to deal with the growing number of people suffering from Alzheimers. Health care, respite care, and other support services are hard to get, and the range of available services often fails to meet the needs of patients or caregivers. Not enough physicians, nurses, social workers, nursing home aides or home health aides are adequately trained in how best to care for persons with dementia.

The Alzheimers Association believes that the only way to address the urgent long term care needs of its patients and its caregivers is the creation of a universal, comprehensive long term care social insurance system. Coverage should be available for all persons who need community or facility based long term care services regardless of age, income, marital status or availability of informal social supports. Eligibility determination for such services should go beyond traditional measures of disability to include functional, cognitive or behavioral limitations including the need for supervision because of risk to safety or health or the need for verbal reminding or cueing. Eligibility determinations should be flexible to reflect individual situations. Benefits should cover the entire range of needed services from home and community based services to facility based services. Services should be provided in such a way as to maintain and enhance personal independence in the setting preferred by the beneficiary and the family. Reimbursement

coverage should extend to non-medical services and supplies needed to maintain patients at home, including the purchase of consumable personal care supplies. The program should assist families and other caregivers (when present) and family caregivers should play a major role in decision making about care coordination. Care delivered in a facility should be covered in its entirety, regardless of the length of stay. Adequate education and training for long term care providers is an essential component of care and must include instruction specific to the care needs of dementia patients. The program should also offer education and training for informal caregivers. The program should ensure high quality care and access to services for all. Research should be conducted on more accurate measures of disability and on the adequacy of services to meet patient and family long term care needs.

The Alzheimers Association proposes that a new public long term care program be enacted along the lines of the eligibility, benefits, training and program principles I have just outlined. It should be based on the traditional social insurance concept and the financial risk should be spread as broadly as possible. Means tested programs such as Medicaid should not serve as the foundation of the federal long term care system. The new program should be supported through sources of financing which are progressive. Protection from out of pocket costs for low and moderate income persons

should be provided. Cost containment measures should be built into the program while quality assurance controls are also incorporated. The system should meet consumer needs while operating as efficiently as possible.

The Alzheimers Association recognizes that Alzheimers Disease and related disorders patients are just one of the many groups requiring long term care services, although we are the largest such group. In 1988 our Association joined as a lead partner in the national Long Term Care Campaign in an effort to join forces with other groups sharing similar concerns. We have joined the public debate which this proposal will undoubtedly create. We applaud Senator Simon's efforts to maintain and highlight the importance of the long term care issue for the national agenda through these hearings.

References:

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* The DHHS Advisory Panel on Alzheimer's Disease draft Introduction p. 1. "The number of persons with dementia is difficult to determine precisely, and is generally estimated by applying a percentage found in studies of a particular community to general U.S. Census figures for the aged.... The research literature in general has indicated that from 4-7 percent of the population over age 65 shows severe dementia and that similar or larger proportion shows milder degrees of dementia. Cross and Gurland (1986) summarized these findings as indicating severe dementia in 1 percent of the population aged 65-74, in 7 percent of those 75-84, and 25 percent of those 85 or older. If the overall prevalence is conservatively estimated at 15 percent, this represents approximately 4.5 million of the current 30 million citizens over age 65." Cross, P.S. & Gurland, Barry J. (1986). The Epidemiology of Dementing Disorders," Contract report prepared for the Office of Technology Assessment, U.S. Congress.

** Huang, Cartwright and Hu, 1988 estimate that senile dementia cost the American economy nearly \$88 billion in 1985 (direct and indirect costs). Huang, L.-F., Cartwright, W.S., & Hu, T.-H. (1988) The Economic Cost of Senile Dementia in the United States, 1985. Public Health Reports, 103 (1, January-February), 3-7.

*** 1985 Nursing Home Survey; preliminary reports from NCHS

LONG TERM CARE AND ALZHEIMER'S DISEASE

EXTENT OF PROBLEM

- o More than 2.5 million Americans suffer from Alzheimer's Disease, a neurological disorder that attacks the brain and leaves its victims unable to care for themselves. An additional 1.5 or more million Americans suffer from a related dementing disorder.
- o Alzheimer's Disease affects at least one person in 20 between the ages of 65 and 75, and over 25 per cent of persons over 85. There are also many patients are under the age of 65. It is the fourth leading cause of death among older adults.

IMPACT ON SOCIETY

- o Most Alzheimer patients will need care at each level along the continuum of long term care -- from day care to home health to nursing home care.
- o 70 percent of Alzheimer patients are cared for at home at an estimated average cost of over \$18,000 a year, (which includes out of pocket costs and lost wages). Neither Medicare nor most private insurance plans cover the cost of care and treatment of Alzheimer patients at home. Most home care is also not covered by medicaid in most states.
- o Alzheimer's Disease usually claims 2 victims - the patient and the family caregiver. Since Alzheimer's Disease runs a prolonged course, lasting anywhere from 5 to over 20 years, families caring for a loved one at home must endure years of physical, emotional, and financial hardship. Oftentimes, the services they need -- such as respite care and adult day care -- are too expensive, inaccessible or unavailable altogether.
- o Victims of Alzheimer's Disease constitute nearly two-thirds of all nursing home residents in this country. Families must now impoverish themselves before Medicaid will cover the cost of long term nursing home care for these individuals. Neither medicare nor private insurance covers the type of nursing home care needed by Alzheimer patients; the average cost is over \$25,000 per year.
- o Current victims of Alzheimer's Disease are not insurable by current private health or life insurance policies

LONG TERM CARE IS THE ANSWER

- o Long term care is good social policy and good economic policy as well. Providing the appropriate level of care

for an Alzheimer victim can slow the progression of the disease, thereby improving the quality of life and reducing the overall cost of health care.

- o Universal and comprehensive publically-supported long term care insurance protection for Americans of all ages and incomes is the key to a national solution to long term care, the Alzheimer's Association believes.
- o the program should provide a full continuum of high quality care in a cost-effective manner.
- o Special needs for Alzheimer patients and families in long term care policy include special training of persons providing care for dementia patients, appropriate services reimbursed under the plan and service eligibility criteria that appropriately measure service needs of dementia patients.

* Throughout the term Alzheimer's Disease is used as a shorthand to refer to "Alzheimers' Disease and related disorders" patients or to all "dementia" patients.

ALZHEIMER'S ASSOCIATION, PUBLIC POLICY COMMITTEE DRAFT
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ELIGIBILITY CRITERIA FOR DEMENTIA PATIENTS FOR LONG TERM CARE
LEGISLATION REVISED MARCH 7, 1989

REVISED ELIGIBILITY LANGUAGE drawing on work by Association members, Bob Cook-Deegan and Katie Maslow of the OTA, U.S. Congress (February 1989), and the DHHS ADVISORY PANEL on AD.

WE STRONGLY RECOMMEND THAT ESSENTIAL ELEMENTS OF ELIGIBILITY CRITERIA BE DEVELOPED BY CONGRESS AND NOT LEFT TO ADMINISTRATIVE AGENCIES.

FIRST, THE PREFACE TO LONG TERM CARE INSURANCE OR OTHER LONG TERM CARE SERVICE BILLS SHOULD STATE THAT THE INTENTION OF THE LEGISLATION IS TO INCLUDE SERVICES NEEDED BY DEMENTIA PATIENTS.

HISTORICALLY, SERVICE PROGRAMS IN GENERAL, AND LONG TERM CARE PROGRAMS ARE NO EXCEPTION, OFTEN EXCLUDED THOSE SUFFERING FROM DEMENTING ILLNESSES FOR VARIOUS REASONS, INCLUDING ELIGIBILITY CRITERIA WHICH EMPHASIZED MEDICAL ILLNESS OR PHYSICAL DISABILITIES. IT IS THE INTENT OF THIS LEGISLATION TO ENSURE THAT DEMENTIA PATIENTS RECEIVE THE SERVICES NEEDED BY THEM AND THAT ELIGIBILITY CRITERIA AND SERVICES OFFERED ARE RESPONSIVE TO THE CHARACTERISTICS AND NEEDS OF DEMENTIA PATIENTS.

ELIGIBILITY CRITERIA:

1) PERSONS WHO ARE UNABLE TO PERFORM BECAUSE OF PHYSICAL OR COGNITIVE IMPAIRMENT (I.E. BECAUSE OF PHYSICAL DISABILITY OR WEAKNESS, OR A NEED TO BE REMINDED VERBALLY TO INITIATE AND COMPLETE THE TASK, INABILITY TO PERFORM THE TASK APPROPRIATELY, INABILITY TO BREAK THE TASK INTO UNDERSTANDABLE STEPS, OR DEPENDENCE ON CUEING ON HOW TO PERFORM EACH TASK OR STEP) AT LEAST TWO OF THE FOLLOWING ACTIVITIES OF DAILY LIVING: BATHING, DRESSING, TOILETING, TRANSFERRING, AND EATING;

OR

2) PERSONS WHO HAVE SUFFICIENT COGNITIVE OR JUDGMENT IMPAIRMENT SO AS TO REQUIRE SUPERVISION BECAUSE THEY CREATE A SAFETY HAZARD OR POSE A DANGER TO THEMSELVES OR OTHERS OR ENGAGE IN DANGEROUS OR OTHERWISE SERIOUSLY INAPPROPRIATE BEHAVIORS, IF LEFT UNSUPERVISED. FOR INSTANCE, THE NEED FOR SUPERVISION AND OTHER SERVICE ELEMENTS MAY ARISE DUE TO INAPPROPRIATE BEHAVIORS ON THE PART OF THE PATIENT SUCH AS STRIKING OUT, PHYSICAL THREATS, VERBAL ABUSE, GETTING LOST OR WANDERING, OR FORGETTING TO PERFORM ACTS ESSENTIAL TO SAFETY, OR FREQUENT CONFUSION AND DISORIENTATION BECAUSE OF MEMORY LOSS OR OTHER IMPAIRMENTS IN COGNITION. SERVICE NEEDS COULD ALSO ARISE FROM SUCH INAPPROPRIATE BEHAVIORS WHICH KEEP THE INFORMAL CAREGIVER AWAKE ALL NIGHT FREQUENTLY ENOUGH THAT THE CAREGIVER IS UNABLE TO WORK AT GAINFUL EMPLOYMENT OR FUNCTION AS CAREGIVER DURING THE DAY.

THIS CRITERION COULD BE OPERATIONALLY DEFINED TO INCLUDE MEASURES OF COGNITION AND MENTAL STATUS AND ASSESSMENT OF THE SUPERVISION NEEDS OF THE PATIENT. IN ADDITION, ECHOING THE DRAFT REPORT OF THE DHHS ADVISORY PANEL ON ALZHEIMER'S DISEASE, "ELIGIBILITY MIGHT BE BETTER DETERMINED ACCORDING TO A SET OF GUIDELINES SUPPLEMENTED BY KNOWLEDGEABLE JUDGMENT ON THE PART OF EXPERTS WHO HAVE NO FINANCIAL INTERESTS IN THE LONG TERM CARE SYSTEM THAN BY RIGIDLY MEASURED CRITERIA."

THE FOLLOWING LANGUAGE WAS DEVELOPED DURING & AFTER MEETING ON AUGUST 23, 1988 AT NIA SPONSORED BY ALZHEIMER'S ASSOCIATION AND CO-SPONSORED BY NIA AND PREDATES THE PRECEDING.

I. Modify (add on or redefine) language laying out Activities of Daily Living as eligibility criteria:

needed assistance* or supervision can include need for "verbal reminding or physical cueing."

In the case of dementia patients, the patient cannot perform the activity of daily living independently or without assistance, either because they are totally helpless and can do nothing themselves, or, during earlier stages in the disease because they lack the judgment, initiative or memory of how to do the task at all or appropriately and because they need a person present to break down the task into understandable steps, verbally remind them to initiate the task or each step and to physically cue them how to do it, or to initiate the task or step.

* such as referred to in one bill as "inability to perform 'without substantial assistance from another individual' at least two activities of daily living"

II. The general format for the eligibility criteria should be as follows:

The patient meets at least one of the following criteria:

- A. Functional disability (e.g. redefined ADLs)
- or
- B. Cognitive disability (cognitive impairment)
- or
- C. Behavior problems of specified nature or consequence
- or
- D. Needs supervision ---for safety and other reasons

The patient has sufficient cognitive or judgment impairment so as to create a safety hazard to himself or others if left unsupervised. (added as an "or" to revised ADL criteria (A))

This language combines items B. and D. above into a much better eligibility criteria than either one constitutes alone. (The closest conceptual parallel here is why young children cannot be left alone)

The principal relevant criteria not included in this phrasing is **BEHAVIORAL PROBLEMS** that could independently lead to service needs. Some reference may need to be included to this as well on the list of alternative eligibility criteria



BIOGRAPHICAL SKETCH: EDWARD F. TRUSCHKE

Edward F. Truschke is President of the Chicago-based Alzheimer's Association, a position he has held since April, 1987. The Alzheimer's Association is a national, non-profit organization dedicated to "standing by" the 2.5 million Alzheimer patients and their families. Truschke was also recently appointed Secretary General of Alzheimer's Disease International(ADD), a group composed of 22 member countries committed to increasing worldwide cooperation to find a cure for Alzheimer's Disease.

Prior to his joining the Association, Truschke was president of BankAmerica Foundation and Senior Vice President of Corporate Community Development. His responsibilities included BankAmerica Foundation/Contributions, Social Policy, Program Strategy and Planning and Community Relations.

Prior to BankAmerica, Truschke was manager of corporate responsibility at Xerox Corporation and Vice President of the Xerox Foundation.

Truschke is on the Board of the National Health Council and the Coro Foundation, a training program for leadership development.

A native of Evanston, Illinois, Truschke was educated at Carthage College in Wisconsin and at the University of Oregon.

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ALZHEIMER'S DISEASE AND RELATED DISORDERS ASSOC. INC.

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Senator SIMON. I thank you. And let me just, because your presence hits one other need that we have, and that is the need for medical research. We need, frankly, as a nation to do more in this area. You mentioned 2 1/2 to 3 million people who suffer from Alzheimer's. I am sure someone has made some kind of cost estimate of what that costs the nation. Do you have any—forgetting the human agony, like Mr. Spiro's story, cost estimates?

Mr. TRUSCHKE. The National Institute on Aging have, when you look at the cost of caring and lost cost of productivity, both in terms of the victim and caregivers who have to give up often times a lot of their earning power to care for the victim, you are talking in estimates of upwards to \$80 billion a year for the cost of Alzheimer's disease. We are spending, as a nation, on average \$30 a person, a victim, a patient for research at this point in time. And while certainly in the last six to seven years the Congress and leadership had certainly, with the efforts of you and others, your colleagues, increased that amount of research spending, but again, for a disease that is costing this country \$80 billion a year, we are spending on average only \$30 per patient in research.

And while, as our association is very concerned about finding the ultimate cure, the cause and cure, because we still don't know the cause for the disease, we of course keep advocating very strongly for increased researched. While at the same time, recognizing that there needs to be attention paid to countless thousands and hundreds of thousands, and millions of people who day in and day out are on the front lines caring for their loved ones with this horrendous disease.

Senator SIMON. So what we really need is a two prong approach, and it is not simply Alzheimer's. It is also arthritis, it is diabetes, it is a lot of other things. Number one, to take care of those who suffer from these problems, and number two, to do research so that fewer people in the future will have to suffer.

Let me thank all four of you and the other panelists. This will conclude the formal part of our hearing.

[Whereupon the subcommittee adjourned subject to the call of the chair.]

